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ABSTRACT

The study is a followup of one carried out in 1977 in South Wales examining problems created by the presence of a mentally handicapped child in the family. Parents of the followup sample, representing only one-third of the original, were interviewed regarding the handicap and its specific effects, family practical needs and problems, family life, medical services, education, and support. Results are analyzed separately for each topic, and as a whole, show continuing high levels of problems experienced by the families involved. Areas of continuing concern included problems in family management and housing and the availability of specialist equipment. Growing concern was noted for post-school provision. Parents appeared to be more satisfied with educational and medical provisions than they had been in the original study. However, the majority reported a continued lack of information about services available to the handicapped and their families. (CL)

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WHOSE CHILDREN NOW?

Graham Upton and Hazel Rendle[1]

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'Whose Children Now?' is a follow up study of the children and families involved in the project known as 'Whose Children?'(Reid, 1979). This study, like the original one, was initiated and financed by the Porthcawl Spastics Aid Group, to whom the authors are grateful for their patience and support. Thanks must also go to the Local Authority personnel, particularly the Headteachers of the Special Schools involved, for the support they gave in helping us to 'track down' the original sample. The authors would also like to express their gratitude to all of the families who took part in the project, for the time they gave, for their helpfulness and interest and not least for the innumerable cups of coffee and tea they provided.

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INTRODUCTION

In 1977 the Porthcawl Spastics Aid Group commissioned a research project to investigate the problems created by the presence of a mentally handicapped child in a family. The study focused on one county in South Wales and involved a survey of some 120 families (one third of all the families with a mentally handicapped child in the area). The survey was conducted in 1977 and the results were published in 1979 as 'Whose Children?' This study provided some remarkable evidence of the problems experienced by parents and their perceptions of the support offered to them. In particular, it highlighted the practical problems parents experience in adapting their homes to accommodate their child's handicap; the difficulties involved in household management; the higher level of attention required by the handicapped child and the problems this creates for family life; the problems of transportation experienced, particularly by families without a car, and the consequent high degree of 'housebound' families this created; the perceived inadequacy of professional support and information services and, finally, the parents' over-riding concern for their children's future welfare.

In the period since that project was carried out many changes seem to have occurred both in attitude towards the mentally handicapped and in the services provided for them.

We have seen the International Year of Disabled People; the Warnock Report has been published; the 1981 Education Act has re-classified these children as having severe learning problems rather than as being 'Educationally Sub-normal (Severe)'; and there has been a growing trend to de-institutionalize many of these children and adults), witnessed by the fact that the hospital school involved in the initial study no longer exists and the emergence of projects, like the nearby NIMROD scheme which have focused on sensitizing the public to the needs of the mentally handicapped and the improvement of community resources.

In this climate it seemed potentially interesting to discover whether these changes were perceived by parents to have had any influence on family life. With the financial support of the Porthcawl Spastics Aid Group a follow-up study was consequently planned to look at these families 'five years on'. The original sample included children from the complete school-age range (from three to seventeen). Five years on about one third of the group could be expected to have left school. In addition to following up the issues raised in the original study the experience of post-school life seemed a new dimension which would extend the original study in a most worthwhile way. This report contains the details of the follow-up study that was subsequently carried out.

CHAPTER II

THE STUDY

AIMS

The aims of the study were to follow up as many families as possible from among those involved in the 'Whose Children?' project in order to:

1. discover just what had happened to this group of children in the intervening five years;

2. look at any changes which had occurred in family life in that period;

3. examine any changes in the problems of management, housing and finance which these families now faced;

4. see whether their perceptions of the adequacy of support services had changed, and

5. look in particular at the experiences of those young people who had left school and to ascertain their families' perceptions of the adequacy of services and support for this post-school age group.

PROCEDURES

The original intention had been to contact all of the families who had been involved in the 1977 study who were

still living in the area and to interview all who were willing to take part in a follow-up study. In the event this proved to be more difficult than expected. A major problem was encountered when it was discovered that no record had been kept of the names or addresses of the families who had participated in the original study. Making contact with the families proved to be a laborious and time consuming process. After discussions with Local Authority personnel it was concluded that the only reliable means of identifying the original sample would be to go back to the records of the seven special schools from which that sample had been drawn. In one of these schools this produced rapid results as the Headteacher had made a note of the children involved in the project. In the other schools no records of the project had been kept and the reconstruction of the list of children was made difficult by the fact that two of the schools had been closed down and replaced by a new school and an assessment unit and that four of the schools had had new Headteachers since 1977.

In the case of the school where a record had been kept of the children who had been involved in the study, contact with parents was made by way of a letter requesting their cooperation once again. In the other five schools lists had to be compiled of all children who could possibly have been part of the original sample. This was based on the school's admissions register for the school year ending July 1977. Some children were excluded from this list because their personal details did not tally with the sample data (e.g. if their date of birth did not

accord with the age of any child listed in the report of the original study) and no attempt was made to contact a number of families where it was known that the child had died.

Eventually some 258 letters were sent out asking parents to confirm whether they had been involved in the original study and, if so, whether they would be prepared to cooperate in the follow-up. While this meant that letters were sent to a large number of families which had not been part of the original sample the authors felt that this was the only way to ensure that contact was made with all parents who could conceivably have been involved. A printed reply slip and a stamped addressed envelope were provided to facilitate replies.

The response to this request was, in fact, very disappointing. Replies were received from only twenty-nine families who said they had participated in the earlier study and one of these indicated an unwillingness to be involved again. However, a limited response to such a written request is not unusual in research of this nature. A reminder letter was sent to those parents who were known to have taken part and who had not replied and a series of home calls made in the hope that personal contact would prove more effective than postal contact. As a result of these two measures the sample size grew to 40 families (one third of the original sample). This was still less than the authors had hoped for (50% of the original group was the initial target), but proved to be all of the families whose original participation could be reasonably established

and who were willing to participate again. A number of families expressed a willingness to participate, (for example, 14 wrote in after the initial letter) but either knew that they had not been involved in the original study or could not remember the original study. Indeed, this inability to remember the previous study was widely reported and directly accounted for the non-inclusion of many families (and possibly the non-response of many others). In view of the length of the original interview and the publicity that was attracted by 'Whose Children?' the parents' inability to remember it seems surprising. On the other hand to expect families to remember a one-off interview with an unknown researcher some five years previously may be to underestimate the seriousness of the problems faced by these families which was so clearly documented by the original study.

THE SAMPLE

While the sample for the follow-up study thus represented only one third of the original sample it soon became clear that it was remarkably similar in composition to the original.

In Table 1 it can be seen that distribution of the ages of the children in the two studies followed a very similar pattern.

Table 1: The Age of the Children Classified According to School-age Groupings

	No.in 1977	Expected No.in 1982	No.in 1982
children of pre-school age (3-4 incl.) in 1977	6	2	2
children of infant school age (5-7 incl.) in 1977	22	7	8
children of junior school age (8-11 incl.) in 1977	43	14	12
children of secondary school age (12-17 incl.) in 1977	49	16	18
	120		40

In Table 2 it can be seen that the proportion of boys to girls in the follow-up study differed slightly from that of the original study. However, the difference is not large and as sex differences played little part in the findings of the original study this difference seemed to be of little import.

Table 2: Sex of Children

	1977	1982
male	60%	50%
female	40%	50%

In Table 3 it can be seen that the types of handicap present in the follow-up group were very close to those identified as characterizing the original sample.

Table 3: Nature of the Handicap

	% in 1977 sample	% in 1982 sample
cerebral palsy	24%	20%
down's syndrome	23%	30%
mental retardation	16%	17.5%
epilepsy	16%	17.5%
spina bifida/hydrocephalus	7%	7.5%
encephalitis	3.3%	2.5%
autism	3.3%	2.5%
hydrocephalus	2.5%	2.5%
muscular dystrophy	2.5%	0.0%
others	2.0%	0.0%

Family backgrounds show some minor variations from the original pattern but the variations are slight. In Table 4, for example, it can be seen that the fathers' occupations in the original and follow-up samples were similarly distributed between non-manual and manual groupings.

Table 4:	Fathers' Occupations	
	1977	1982
non-manual	29%	27.5%
unskilled, semi-skilled and skilled manual	71%	72.5%

The marital status of the parents shows some change between the original and follow-up study.

Table 5 needs some explanation, however. None of the parents who were divorced at the time of the original study were traced by the follow-up. Therefore all the divorced parents in the 1982 sample had become divorced since 1977. This represents an increase which is not apparent from the figures. By contrast, all the widows included in the original sample also took part in the follow-up, thus constituting a high proportion of the 1982 sample. The figures indicate that one widow has been included in the 1982 survey who was not part of the original sample (although part of the population from which that sample was taken).

Table 5: Marital Status of the Parents

	% in 1977	% in 1982
married	83%	75%
foster parents	1.66%	-
separated	1.66%	-
divorced	9%	10%
unmarried	1.66%	-
widowed	3%	15%

The type of housing enjoyed by the families in the follow-up sample differed from that of the families in the original sample and shows a slight shift towards families who own their own homes as can be seen in Table 6.

Table 6: Types of Housing

	% in 1977	% in 1982
private property	51%	62.5%
property rented from Council	41%	33%
property rented from National Coal Board	5%	2.5%
other	3.	-

While this is not a major difference, and probably partly reflects the national increase of 5% in home ownership in the intervening period, it should be borne in mind when considering any results of this follow-up which relate to housing or which have financial bases or implications.

Overall, this data does suggest that the follow-up sample is sufficiently close to the original in terms of its key characteristics to make it possible to compare findings between the two surveys with some degree of confidence.

THE INTERVIEWS

Information for the follow-up study was collected by means of a structured interview during which a detailed questionnaire was completed in relation to each family. A copy of this questionnaire is included as an Appendix to this report. The questionnaire is based on that used for the original study but has been modified to gather the additional information required for the follow-up and particularly in relation to the post-school experience of the children and their families. It contains

seven sections as follows:

1. Background information about the child and the present family situation.

2. The Handicap and its Specific Effects. As the heading suggests this focuses on the nature and extent of the child's handicap.

3. Practical Needs and Problems. This includes questions on housing, equipment, allowances and transport.

4. Family Life which looks at the effects of the presence of a handicapped child on family life and focuses particularly on any changes which have occurred as a result of children getting older.

5. Medical Services. This looks at the support parents receive from medical services and their perceptions of the adequacy of the help.

6. Education which includes sections on post-school provision as well as reviewing recent developments in school-age resources.

7. Support which considers not only formal support services but also the importance of informal support.

All of these interviews took place in the parents' homes but were all arranged in advance by telephone or by personal contact. Most of the interviews took place between May and

October 1982 and lasted, on average, between two and three hours each. All interviews were tape recorded for subsequent use in completing the questionnaire. The interviewer asked to see both parents wherever possible but this occurred only in 42.5% of the interviews.

The information gathered in the interviews and set out in this report necessarily constitutes the parents' perceptions of the situations under consideration and may not always accord with the views of others.

CHAPTER III

RESULTS OF THE SURVEY

CHANGES IN FAMILY LIFE

What Has Happened to the Children?

Fifteen of the 40 children in the sample (37.5%) had left school during the past five years. Only one of these had gone into residential care. The 25 children who were still at school were all living at home either with the mother or with both parents, though sadly one of these children, a boy of eleven, died during the period in which the study was undertaken.

What Has Happened to the Families?

In 19 cases (47.5%) the composition of the family had changed since the previous study. These changes are shown in Table 7. In some homes more than one change had taken place.

Table 7: Changes in the Composition of Family

Nature of Change	Number
divorce of parents	4
death of one parent	2
death of handicapped child	1
death of grandparent	2
children moved out of parental home	11
handicapped child in residential care	1
birth of another child	2
divorced son returned to family home with his child	1

In each of the cases of divorce the handicapped child had remained with the mother. The parents whose child died had been divorced a few months previously.

GENERAL HEALTH

The Handicapped Children

In 22 cases (55%) the parents said that there had been no change in their child's general health during the last five years but in 12 cases (30%) they thought that their child's health was worse and one child in the sample had died. On the other hand, in 5 cases (12.5%) the parents thought that their child's health was better.

Many of the parents who said that there had been no change in their child's state of health emphasised how healthy their child was. Some of the changes in both categories were only slight.

Fourteen of the children had fits at some time. For some the onset of these had coincided with puberty and some of the girls had fits mainly before periods. Some of the other children had previously had fits but these were now controlled with drugs. There are no figures available for 1977 but it can probably be assumed that a smaller percentage of the 1982 sample had fits because of the widespread use of drugs in this context.

The Parents

Table 8 shows the parents' view of changes in their own

general health in the last five years. It can be seen that overall parental health also seems to have deteriorated although it clearly cannot be assumed that this is related to the presence of a handicapped child in the family.

Table 8: The Parents' View of their General Health

	No.of families	%
no change	18	45%
both parents' health worse	5	12.5%
mother's health worse	12	30%
mother had died	1	2.5%
father's health worse	2	5%
father had died	1	2.5%
mother's health better	1	2.5%
Total	40	

The mother who said that her health had improved thought that this was because since her divorce she no longer had to cope with the strain of an unhappy marriage.

Of those who reported no change, one mother said that she suffered from "stress" and one couple said that they were both "stressed". Two mothers in the older age-group commented that they were "slowing down" and "not feeling so good now".

Reid (1979, p.39) comments that "the general health of both the mothers and fathers in the sample can only get worse as they get older". The present study certainly suggests a

trend towards worsening health, particularly where the mothers are concerned, though it should be noted that in 45% of the families the parents reported no change in general health.

"Baby-sitting" and Temporary Care

Table 9: Frequency of Parental Evenings Out

	Number
once a week or more	9
once a month or more	7
more than twice a year but less than once a month	8
once a year or less	5
Total	29

Some of the parents in the last two categories said that they could go out more often if they wished.

Table 10 shows who looks after the child when parents go out for an evening. Note that some parents have help from more than one source.

Table 10: Arrangements for Looking After Child During Parents Evening Out

	No.	% of those looked after
siblings	13	45%
grandparents	9	31%
other relatives	2	7%
social services sitter	3	10%
paid sitter	2	7%
child goes to local authority hostel	2	7%
Total	36	

It is not possible to make an exact comparison with Reid's figures because the present study records sitters in more than one category for some of the families. However, the present results suggest that sitters other than relatives are playing a greater role in looking after the children than previously.

Again while Reid has no figures with which to compare, it seems likely that siblings have taken over from grandparents as the most frequent sitters. The present study shows that other relatives play a very small part in the provision of baby-sitting.

A problem reported in some families was the availability of a suitable baby sitter. The parents who said they did not have evenings out were asked whether they would go out if they had a suitable sitter. Of these, 5 said they would not go out, 4 said they would go out and one was unsure.

Those who thought they would go out were further asked who they would consider to be suitable to look after their child. One said that it would need to be a mature person, but that the social services had never offered any baby-sitting help and that their local voluntary organisation was probably too scattered to form a self-help group. Another parent thought that a qualified nurse would be necessary and a third said it would have to be someone who knew her son and what he might do, particularly because he had daily epileptic fits. The fourth parent could not think of anyone who would be able to help.

One parent (not in the above group) had approached the social services about baby-sitting help but was told that this was not provided at weekends, the time when she felt they were most likely to need it.

A number of parents commented that their own parents were either no longer able to cope with their handicapped child or would not be able to cope for much longer. In addition to this, their greatest source of baby-sitting help, now provided by older siblings, was likely to diminish if and when siblings left home and/or had their own families. This had already happened in a number of cases. This likely decrease in family help suggests that the need for baby-sitting help from other sources will increase in the future. The parents were also asked who would look after the child if there was an unexpected family problem resulting in the mother's temporary absence. The results are shown in Table 11.

Table 11 Person who could look after the child in the event of the mother's temporary absence

	1977		1982	
	No.	%	No.	%
father	63	54%	16	40%
siblings)			8	20%
grandparents)	29	23%	4	10%
other relatives)			3	7.5%
friend or neighbour)			1	2.5%
residential care	26	21%	13	32.5%
remain with mother	2	2%	-	-
already in residential care			1	2.5%

(Note that answers may be in more than one category because some parents offered several alternatives)

These figures are difficult to compare because Reid does not distinguish between siblings, grandparents, other relatives and friends and because the 1982 sample gave answers in more than one category. However, the figures suggest an increased reliance on siblings for care within the family (as for evening baby-sitting) and an increased reliance on short-term residential care facilities. The breakdown of the categories in the present study also suggests that the support of friends and neighbours would not normally extend to respite care.

Family Holidays

As the children have grown older families seem to have been able to enjoy more frequent family holidays.

Table 12 shows the frequency of family holidays during

the last five years. For the purpose of comparison with Reid, those who had four or more holidays during the last five years have been included with those who had taken them annually and those who had two or three holidays in the last five years have been included with those who have taken them every other year. One holiday in the last five years has been classed as "very infrequently".

Table 12 Frequency of Holidays

	1977		1982	
	No.	%	No.	%
annually	46	38%	22	55%
every other year	7	6%	6	15%
very infrequently	7	6%	5	12.5%
never	60	50%	7	17.5%
Total	120		40	

This shows a considerable increase in the frequency of holidays in the five-year period since 1977. This may reflect the fact that very few of the families now had young children and therefore the only family member needing supervision or extra care was the handicapped child (or young person).

It is also possible that more families are able to afford holidays now that a greater number of handicapped children are entitled to the mobility allowance (though perhaps this needs to be offset against the high percentage of families in the sample with no earned income). A number of the parents said that

part of their allowances went towards holidays. There were also fewer problems of transportation than in 1977 and 62.5% of parents now owned a car. It may also be that there has been an improvement in public attitudes which has made it easier for parents to take their handicapped children on holiday.

Three of the handicapped children were not taken on the family holiday but were placed in short-term care. One of these families had taken their child with them once but "she was miserable". In 4 other families some of the family members had additional holidays without the child, who was placed in short-term care or looked after by relatives. There were no major problems with these arrangements and a number of the parents said that their child loved being at the hostel. The main problem was for the parents themselves, particularly the mothers, who sometimes had "guilt feelings" about leaving their child, even though they knew they needed the break.

Of the families who took their handicapped children on holiday 22 reported that they had had no problems and 8 had had minor problems only.

Only one of the 7 families who did not have holidays thought that they would go if there was somewhere suitable to leave their handicapped child. This parent considered that there should be local short-term care available and was hopeful that this would eventually be provided. According to the recent District Plan for her area, a site had been earmarked for a residential home

for the mentally handicapped. However, this parent said that they would still prefer to take their handicapped daughter on holiday with them if there was a "quiet country place" which catered for the needs of the whole family.

A number of the children and in some cases the whole family had had special holidays provided by the Rowntree Trust, the social services department or a charitable organisation. However, where access to such provision is concerned, some families still seem to slip through the net. In one family, for example, where the father had died eight years previously, the mother and the eighteen year-old handicapped young person had not had a holiday since the child was a baby. The mother said that they had never been offered a special holiday and that she had never heard of the Rowntree Trust. As in the original study, the majority of these holidays were much appreciated. However, several parents said that their children were homesick away from the rest of the family. One mother hadn't wanted her son to go, but had been told by a Health Visitor that she was being very selfish. When the child was away she received daily telephone calls to say he was unhappy. "What sort of holiday is that?" (Mother).

One couple, whose daughter had spent a few days at a holiday home, said that it was a lovely place but that there was not enough supervision. When they had gone to collect her she was "absolutely stinking" because she hadn't changed her clothes at all, not even underwear. The staff had evidently thought that she would manage by herself, although the parents said they

explained that their daughter needed either to have things done for her or to be told to do them. They understood that these places depended on volunteers and that the helpers had done their best, but they wouldn't let her go again. At the same time they said that if their daughter could look after herself it would have been ideal.

Two families commented that they would much prefer to have the money to use for a holiday of their own choice. In one of these cases the parents said they would love a holiday and that they had been offered one of these special holidays. They turned it down because they were not keen on the idea of holidays solely for mentally handicapped children and the mother disliked the particular seaside town where they were invited to go.

In 2 cases parents felt that the management problems involved in taking their daughter on holiday were too great to contemplate. In the other 4 cases lack of money was described as the prohibitive factor.

Relationships

The parents were asked how they thought their child's growing older had affected relationships within the family. While many families reported no change or an improvement in relationships, a sizeable minority claimed that relationships had suffered. In 18 of the families (45%) the parents said that relationships had not been affected at all. In 4 families (10%) the parents said that family relationships had improved as the

handicapped child got older and in 12 cases (30%) the parents considered that relationships had become more difficult. In some cases the improvement or deterioration was said to be slight. In one case the mother and father disagreed on the answer. (The father said it had made no difference and the mother thought it had made relationships more difficult). In another case the family situation seemed to be too complex for a straightforward answer while the question was not applicable to the remaining 4 families (10%), either because the child was in residential care or because the family only consisted of the handicapped child and one parent.

It is interesting to note that in 3 of the 4 cases where the parents considered that family relationships had improved, the child concerned was a Down's Syndrome child. This probably reflects a tendency for management problems connected with Down's Syndrome children to decrease as the children get older.

The parents were also asked about relationships with people outside the family. While 25 families (62.5%) said that their handicapped child's growing older had made no difference to these relationships, 14 families (35%) considered that relationships had become more difficult. In one case, one parent thought that relationships with other people had become more difficult while the other thought that they hadn't changed at all. In many cases the parents thought that having a handicapped child either prevented them from making new friends or contributing to their losing friends because they were unable to get out to

see them. Several parents commented that it was sometimes relatives outside the immediate family with whom relationships were difficult.

Interestingly, there was little evidence that the handicapped child's growing older created problems for other children in the families. The parents who had other children at home were asked whether these siblings invited friends to the house.

Table 13 Extent to which siblings invite friends to the house

yes	20	50%
no	4	10%
not applicable	14	35%
varies with child	2	5%

In one of the 4 cases where siblings did not invite their friends to the house the parents believed that this was a function of their personality and that it was definitely not connected with their handicapped sister.

In other words there were only 3 families (7.5% of the sample) where it seemed likely that siblings were deterred from bringing their friends home by the presence of their handicapped brother or sister. Nevertheless, this does constitute a problem, even if only for a small percentage of families.

CHANGES IN PROBLEMS OF MANAGEMENT

Some of the problems of management reported in the original study were reported as much less severe by the time of the follow-up. With increasing age, however, different management problems were beginning to appear. When the parents were asked what aspect of the care or management of their handicapped child caused them concern they reported that they found it most difficult to cope with:-

a) the increasing difficulty of lifting as children become heavier and parents get older;

b) the children's need for constant care and 'watching' and the consequent feeling of parents that they were 'tied';

c) coping with some form of difficult or anti-social behaviour such as tantrums, violent outbursts or stubbornness.

A number of parents commented that the problems were not always apparent to people outside the family. "When you come into a home and see how people seem to be coping it doesn't show the real picture".

Housing

Seven of the families (17.5%) had moved house during the last five years. (This level of "local mobility" may have contributed to the failure to contact a high percentage of the families in the original sample). Two of these families had moved for reasons not connected with their child. The other 5 families, 3 of which were council house tenants, had moved

to make it easier for them to cope with their handicapped child. In each case this had been successful and in no case had there been any problems connected with the move. One family, whose unsuitable housing placement on an estate at the top of a very steep hill was noted by Reid (1979, p.39) had been rehoused in a small development for people with handicaps and health problems. In several cases the move was said to have enabled the handicapped child to have a safe place to play.

A further 5 families said they would like more suitable accommodation. Two of these were owner-occupiers, 2 were council tenants and one was an N.C.B. tenant. Two cases will serve to illustrate the problems they faced. One family lived in a house with two flights of stairs. The handicapped young person was a non-ambulant and the doorways were too narrow for a full-size wheelchair. The house was on an exceptionally steep hill which made wheelchair-pushing difficult. The parents considered that nothing could be done about a move because the house was National Coal Board property. The parents would like to buy a house on the level but cannot afford it. Another family had been unhappy since they were housed on an estate on the outskirts of their home town nine years ago. They said they would like to be nearer to the wife's parents whom they considered to be their only possible source of help. They had recently discovered that they weren't moving up the council list because the forms with medical and other evidence to support their case had been accidentally destroyed with consequent loss of 'points'. They recently had the telephone taken out when the

husband had to take a cut in wages and the wife said she sorely missed the contact with family and friends. The other 3 families, 2 of them owner-occupiers, wanted bungalows or houses with more ground floor accommodation for their handicapped child.

As the children had got older it was noted that increased strain was felt to have been placed on household facilities. Nineteen of the families (47.5%) had had to have alterations made to their house or new fixtures put in in the last five years in order to make it easier to cope with their child's disability. Ten were owner-occupiers, 8 were council tenants and one was an N.C.B. tenant. The alterations carried out are shown in Table 14.

Table 14 List of housing alterations and new fixtures

	No.
bathroom and toilet knocked into one	2
path and paved area made outside	1
2 downstairs rooms knocked into one with door for wheelchair	1
bedroom built downstairs	2
bathroom put in downstairs	1
downstairs extension consisting of bedroom and bathroom	2
downstairs room converted to bedroom	1
handrail for stairs	2
lift	2
hoist	2
handle to raise self in bath	1
step for bath	1
lower bath	1
wall or fence round front garden for safety	3
reinforced window glass	1
central heating	1
handrail for outside steps	1
sliding door to bathroom	1

In 10 cases these alterations had been financed by the local authority. In 3 cases the parents had grants from the local authority which covered one third, half and three fifths of the cost respectively. In one case the parents had help from the Spastics Society. In the other 5 cases the parents paid the full cost themselves. One of these families, council tenants, applied to the social services but were told that no help was available. This was a sore point for the family because it was the only time they had approached the social services for help. In addition, one family had had repairs carried out by the local authority because their child continually damaged doors and windows. However, the last time the mother had applied for a new window she had been told that repairs were no longer being carried out.

One family said that they had had to wait three years for the local authority to put a fence outside and another family said they had waited a year for them to instal a lift. One family was still waiting for a lock to be put on the back door which had been promised 4 years previously. One of the families who had the bathroom and toilet knocked into one were twelve weeks without a cistern. This was a large family with severely handicapped twins and a very elderly member who was seriously ill. There were considerable resultant problems.

Many families still considered that their housing was inadequate to enable them to cope effectively with their child's handicap. Eighteen families (45%) considered that

there was still something about their house which was inconvenient for their handicapped child even though 11 of these families had already had alterations carried out or new fixtures added. Table 15 shows the problems which were considered outstanding.

Table 15 Type of problem with house

	No.
no downstairs toilet	3
no upstairs toilet	1
bathroom too small	1
toilet too small	1
bath too high	4
stairs (sometimes 2 flights)	7
steps to front door	3
doorways too narrow for full-size wheelchair	2
no handrail for outside steps	1
house too small	2
no safety fence for garden	1
difficult or dangerous garden	2
very steep street	1

Another house had very steep steps to the front door but the parents did not consider this to be a problem because, as their child needs constant supervision, there is always someone with her.

The parents were also asked whether they had tried to get anything done about their problem. Eight families said that they had. Two of them were taking action themselves and it is worth noting at this point that some parents saw everything that needed to be done for their child as their responsibility. "She's our child and anything that needs doing for her we'll do. We don't think to ask anyone else for help". Three

families had applied to the local authority and were expecting the work to be carried out and one family was in the process of applying for a grant and was waiting for a visit from the appropriate department. In the other 2 cases, applications to the local authority had been refused. In the first case this was because the house was apparently unsuitable for the proposed alterations. The social services department had suggested a different alteration which might help to alleviate the problem but no decision had been taken on that. The second application was turned down on the grounds of expense. This family had recently been rehoused at their own request but there was a flight of steps up to the front door. It was hard work to get a wheelchair up and down and neither parent was supposed to lift so they had asked for a ramp. It is surprising, to say the least, that this problem was apparently not taken into account, either by the parents or the local authority, before the family was rehoused.

In 10 cases the parents had not tried to get anything done about the problem. Four of these families commented that nothing could be done about their particular problem anyhow. One family who needed a fence for the child's safety, thought that this would not be allowed on the council development where they lived. One mother, whose problem could have been fairly easily solved, said she was afraid of being laughed at if she asked for help. A further family considered that the work was too expensive for them to do themselves but did not know anything about what they were entitled to apply for or how to go about it.

If this overall picture is compared with that of the original survey it would appear that, while there were still major problems, there has been a considerable improvement in the housing situation during the last 5 years.

Equipment

Seventeen families (42.5%) had had new equipment or received money towards the purchase of equipment which in some way related to their child's disability. This is listed in Table 16.

Table 16 Equipment obtained since 1977

wheelchair	8 (incl. 1 electric)
battery car	1
telephone	1
chair or stool for bath or shower	5
plastic inner bath	1
slip mat for bath	1
washing machine	4
tumble dryer	1
bed or money towards bed or bedding	3
portable chemical toilet	2
walking aids	2
money for or towards miscellaneous items (including sewing machine, lounge suite, car, special seat belt)	4

All the wheelchairs were supplied by the Welsh Office except one which was bought by the parents with the help of a collection taken by the nurses at the hospital where the mother worked. The battery car was also bought by the parents. All the bath aids were provided by the local authority social services

department as were the chemical toilets and one of the bedding grants. The walking aids were supplied by the health authority. Two of the washing machines, the tumble dryer, two of the bedding grants and the money towards the purchase of miscellaneous items were provided by the Family Fund (Rowntree Trust) except for the money for the seat belt which came from the Spastics Society. The other two washing machines were being rented or bought on hire purchase by the parents.* The telephone was installed at the parents' expense. They had applied to the social services department for this to be done but were told that this service was no longer available.

Two families were waiting for small pieces of equipment but these had only been asked for fairly recently. Another family had put in a request for a wheelchair about a year before the interview took place but there was some uncertainty as to whether the authorities considered this to be necessary or desirable for their child and it seemed unlikely that an official application had been made on their behalf.

The initiative to obtain the equipment came mainly from social workers and from parents themselves. Suitable items of equipment were sometimes suggested by social workers in response

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* In these cases, the children were incontinent but too old to qualify for help from the Family Fund.

to parents' management problems and in some cases the social worker had applied to the Family Fund on the parents' behalf.

There were a few problems reported in connection with the use of equipment. In several cases the bath aids were said to be either somewhat awkward to use or that the child refused to use them. The electric wheelchair was not yet in use because the user hadn't "got used to the gadgets" yet. The mother said that they were managing with the old one for as long as possible but that eventually they would have to use the new one.

Home Management Problems

A comparison was made between the "self-care" abilities of the 1977 and 1982 samples in order to discover whether there was likely to have been any change in the problems of caring for the children.

Table 17 Self-care abilities of the children

	1977		1982	
	No.	%	No.	%
able to sit without support	88	73%	33	82.5%
able to walk unaided	76	63%	30	75%
some functional mobility though unable to walk	13	11%	4	10%
able to chew and swallow without difficulty	68	57%	27	67.5%
able to drink from a cup	92	77%	35	87.5%
able to feed unaided	79	66%	34	85%
able to dress unaided	21	15%	9	22.5%
continent	44	37%	24	60%

The increase in the number of children who were continent appears to be dramatic. However, the difference in the figures may partly result from a difference in definition. Of the 60% recorded as continent in the 1982 sample, 35% either had accidents, or were very messy or needed supervision or to be taken to the toilet but none of them wore nappies. The great majority of the 40% recorded as incontinent wore nappies all the time, although one child wouldn't wear pads and one mother said she wouldn't put her son in pads in case he reverted to a greater degree of incontinence. All the children who needed to wear nappies received them from the health authority (not the social services department as in 1977). In addition, it must be remembered that there was a higher percentage of Down's Syndrome children in the 1982 sample. However, these explanations seem unlikely to account for the whole of the increase and some of the parents said that their management problems had decreased considerably since their child had become continent or progressed towards continence. One mother, whose son had become dry at the age of fifteen following an operation said "This has changed our life completely". For some parents, however, the problems of incontinence increased as the child got older. This was particularly true when girls began to menstruate. One mother described the mess of double incontinence and menstruation as "unbelievable".

It is worth noting the considerable increase in the children's ability to feed themselves and the very slight increase in their ability to dress themselves. The figures in

both categories include those children who required help with the more difficult procedures involved in feeding and dressing. Dressing presumably continues to be a particular problem because of the degree of coordination required and probably also because children are normally dressing at the time of day when parents have the least time to allow them to try to manage by themselves.

The parents were asked how much progress they felt their children had made in managing to look after themselves in the last five years. The parents' ratings were used in conjunction with a checklist of possible areas or progress which included toileting, dressing and feeding. The results are shown in Table 18.

Table 18: Parents' ratings of their children's progress in self-care during the last 5 years

	No.	%
no progress	8	20%
slight progress	11	27.5%
moderate progress	7	17.5%
good progress	14	30%

For some children, of course, no progress was possible because they had no functional mobility. Others were already fairly competent in some aspects of self-care and therefore a small degree of progress did not indicate inability to do things for themselves. A few of the children were said to

have regressed in some areas.

A comment from one mother who rated her daughter's progress as "mode[illegible]e" expresses the importance of having an adequate concept of "progress" in relation to children with special needs. "We think it's tremendous. The little things that have come have been great".

Speech Problems

85% of the children in the 1982 sample were reported to have some problems with speech as compared with 89% in the 1977 sample. Of the 34 children with speech problems in the 1982 study, 3 could not make themselves understood at all and 15 could only make themselves understood to family and people who knew them well, sometimes by miming. The other 16 could make themselves understood reasonably well though some of these also used mime at times. While there was little change in the percentage of children with speech problems between the two studies, the parents of 50% of the children considered that there had been some improvement in their speech. The parents of all but 2 of the children thought that their children understood at least some of what they said to them though many of them emphasized the need to keep it simple. Some parents thought that their children understood most of what was said to them. In the other 2 cases the parents considered that their children understood very little of what they heard. For many parents the lack of adequate communication was the most frustrating aspect of their relationship with their child.

Sleeping Problems

52.5% of the children in the sample were said to have sleeping problems in comparison with 70% in 1777. However, in only one case the child's sleeping problems did not affect the rest of the family; therefore half the families still had their sleep disturbed at times, many regularly, though the 1982 study shows a definite improvement.

Family Participation in Care

The parents were asked how the extra work of caring for the handicapped child was shared between members of the family. The results are shown in Tables 19 and 20.

Table 19: Parents' perceptions of how they share the extra work of caring for their handicapped child

not applicable (only one parent or 'no extra work' or child in residential care)	12	30%
mother does all	5	12.5%
father helps but mother does most	10	25%
share it all when both parents at home	13	32.5%

This table is complicated by the fact that in some cases the mother was interviewed and in some cases both parents were interviewed though there were no disagreements between these parents as to their answer.

Table 20: Whether siblings help with the handicapped child

	No.	%
not applicable (no sibs. or no sibs at home or sibs too young or no extra work involved)	15	37.5%
yes	20	50%
no	5	12.5%

The sort of help given by siblings fell into three main categories: baby-sitting, practical help and playing with or taking out their handicapped brother or sister.

Some children who had married and left home still helped at times, for example with baby-sitting or having the child to tea. One mother whose other child didn't help said that she didn't want her to be burdened. Another said that she didn't expect her sons to help because they had their own lives to lead. A few parents said that there was some resentment towards the handicapped child on the part of their other children, but this was rare. A few reported times of these children being irritated by their handicapped sib ling. However, the impression given by the parents was that the majority of the children completely accepted their handicapped brother or sister. A number of parents said that the experience had made their other children "grow up quickly". Many of the parents were high in their praise of their children's attitudes and help. "My children have been marvellous". and "They think the world of

her. Not one of them is jealous" were typical comments.

Management Problems Relating to Travelling

Eighteen (45%) of the families said they experienced some difficulties in travelling with their handicapped child. This is considerably less than the 88% recorded for the 1977 sample. However, 62.5% of the 1982 sample families now had their own car* compared with 55% of the 1977 sample.** However, this level of increase in car ownership is clearly not sufficient to account for the apparent decrease in travelling difficulties. It may be that the difference represents a reduction in the parents' need to make regular visits to a medical specialist with their child. At the time of the 1977 survey 97.5% of the sample sometimes visited a specialist whereas this figure was reduced to 57.5% in 1982.

Nevertheless, the travelling difficulties experienced by the 1982 sample should not be minimized. Although 25 families (62.5%) in the sample owned cars it was evident from the conversations that very few of the mothers could drive and that this restricted their lives considerably and it was necessary for husbands to take time off work whenever the child needed to be taken anywhere. In some cases, however, both parents were needed in order to manage the child.

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*This figure does not include cars owned by adult children living at home because the car was not necessarily available for the parents' use and not all the parents could drive.

**It is not entirely clear from Reid (1979,p.25) whether the 55% represents the total number of car owners or only those car owners who experienced travelling difficulties with their handicapped child.

The main problems experienced with public transport were difficulties involved in getting children on and off without help, and the problem of incontinence which created a need to carry a lot of additional equipment. Several parents who had no car said that their children could not walk far enough to use the bus but that if they took the wheelchair this was a problem once they reached the bus. For this reason at least one family could not go further than wheelchair-pushing distance. Some parents were forced to use taxis or to rely on lifts from neighbours. One father pointed out that his daughter could travel on the Inter-City train (to London) because a seat would be taken out to make room for her wheelchair if British Rail was notified in advance but they could not use a local train to connect with it because there was no space for her chair and she could not sit without support. A number of parents who had no travelling difficulties said that they would have problems if they had to depend on public transport.

Only one family mentioned the attitudes of other people as a problem when travelling and in this case it was children who apparently made fun of the handicapped young person.

Some families with their own cars had problems because the child got upset or over-excited or had fits in the car. One couple were concerned because they foresaw that in a year or two they wouldn't be able to get their son in and out of the car. They considered that they would need a large van with a ramp but didn't know how they would meet the expense of this.

FINANCE

Employment

Reid's study gives no figures for the number of parents who were unemployed. There can, however, be little doubt that these figures would have shown a significant increase in view of the current employment situation and of the fact that the area in which the studies were conducted has a particularly high rate of unemployment.

Table 21 shows the employment situation of the 1982 sample.

Table 21: Employment situation of parents in the 1982 sample

	No.	%
both parents in full-time employment	1	2.4%
father only in full-time employment	18	45%
one parent only in part-time employment	3	7.5%
parent retired due to age	2	5%
father retired due to ill-health	3	7.5%
father retired early to help with child	1	2.5%
father (previously unemployed) receives Invalid Care Allowance)	1	2.5%
single parent with no earned income	7	17.5%
father unemployed	4	10%

In 6 of the families where the father had full-time employment the mother had a part-time job. In one family where the father had retired due to ill-health the mother had also retired.

As can be seen from Table 21, 45% of the families had no earned income and a further 7.5% of the families had an earned income from part-time employment only.

Allowances

Table 22 shows the allowances received by the families compared with those received by the 1977 sample.

Table 22: Allowances received by families

	1977		1982	
	No.	%	No.	%
attendance allowance	107	89%	38	95%
mobility allowance	39	32.5%	21	52.5%

Twelve families in the 1982 sample received the day attendance allowance only. In one case where the day attendance allowance was paid for the child in the sample there was a more severely handicapped sibling (the sample child's twin) for whom the full allowance was paid. Mobility allowance was also paid in respect of the twin sister but not the sample child. The percentage of children receiving the mobility allowance had increased considerably since the extension of this form of payment to include children from the age of five upwards. Four families who had applied for mobility allowance had been refused. One family who now received this allowance had had their first application turned down. Another family said they had had a "long and hard battle" to get it.

There were some parents who hadn't applied for mobility allowance because they said they "don't like asking for anything". Others, who felt they had been unfairly treated in relation to either allowance, were reluctant to appeal because of the "hassle" it involved. A number of families claimed that they had never been told officially about the allowances but that they had learned of their existence "accidentally" from sources such as friends, the media or other parents of handicapped children. One family had discovered about their entitlement from a local councillor. Some parents had missed out on payments for many years because they were unaware of their availability.

One father, who had been unemployed, now received the Invalid Care Allowance. His wife said she could not cope with their daughter alone. He had found out about it himself and applied for it. (This payment does not affect the Attendance Allowance, but married women are not entitled to apply for it). Sixteen of the 18 young people who were over the age of sixteen received the non-contributory invalidity pension. The other 2 received their allowance in the form of long-term supplementary benefit. A number of families received means-tested benefits in addition to these allowances.

Table 23 shows the parents' perceptions of whether the allowances they received were sufficient to cover the extra expenses involved in caring for their handicapped child.

Table 23: Parents' perceptions of the adequacy of allowances

	No.	%
yes	17	42.5%
no	17	42.5%
unsure or haven't thought about it	5	12.5%
not applicable (child in residential care)	1	2.5%

It should be noted that many of these families were on very low incomes, some living entirely on state benefits, and it may therefore have been difficult for them to assess how much of their financial plight was attributable to the extra burden of having a handicapped child.

Many of the parents said how helpful the allowances were and how grateful they were for this provision. One parent said "It makes up a little for the life we've got". In particular, a number of families said that the mobility allowances enabled them to have a car which they could not otherwise afford, although, as some pointed out, it certainly did not cover the running expenses or enable them to replace it. 62.5% of the sample had their own car compared with 55%* of the 1977 sample. This is not as great an increase as might have been expected in view of the considerable increase in numbers receiving the mobility allowance. It may, however, be partly accounted for by the fact that the sample included a high percentage of

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* See second footnote on page 40

single-parent mothers who did not drive.

A lot of the children very much enjoyed car outings and the mobility allowance made these possible. One couple said that the only swimming pool they could take their handicapped child to was one about forty miles away where she could walk into the water on the level. Again, the mobility allowance made this outing possible. One couple thought that the allowance should vary according to the degree of immobility. Perhaps the most important comment on the attendance allowance, made by several of the parents, was that while it was a great help it in no way compensated for what the mother could earn.

The extra expenses involved in caring for a handicapped child obviously vary considerably according to the degree of handicap and the particular problems involved. One mother said that her son didn't cost any more to look after than any other child whereas the majority of the parents found that there were numerous extra expenses involved in providing for the needs of their handicapped child. Among the expenses referred to were the cost of clothes and shoes, bedding, heating and the cost of heating water for extra washing. Incontinence caused clothes and bedding to wear out quickly because of the staining and extra washing. Dribbling from the mouth was also a problem. Many of the children were said to need a complete clean set of clothes every day. Those children who could only move about the house by crawling or pulling themselves along were constantly wearing holes in trousers and socks. Many of

the children were difficult to fit. One young woman for example, was very short and stout. Children with weight problems needed larger fittings which were more expensive than normal sizes. Some parents said they had to resort to buying second-hand clothes but as one parent pointed out "Cheap clothes make these children look even worse". One mother said she had to buy new jumpers and vests for her son every week because he pulled them to pieces in excitement when watching television. Many of the children were very heavy on shoes because of the way they walked. In addition, their walking problems meant that good quality, well-fitting shoes were necessary and these were expensive. Incontinence coupled with mal-treatment of furniture caused major expenditure for some families. One mother said that she had had seven lounge suites since her son (now aged fifteen) was two-and-a-half. Beds also needed to be replaced more often than normal in cases of severe incontinence.

Families who received supplementary benefit could claim allowances for clothes and shoes but one mother who received this form of help said that while it was useful it still didn't cover the extra cost of these items.

Several parents found it difficult to meet the cost of regular hospital visiting especially because the attendance allowance was not payable when the child was in hospital. Help with fares for hospital visiting is sometimes available for families on supplementary benefit or on a low income. A

few families had had help with the cost of hospital visiting from the Family Fund but this is not available in respect of children over the age of sixteen. The mother whose child had died had received help with hospital visiting expenses, as well as a death grant, from the voluntary organisation to which she belonged.

EDUCATION

Twenty-four of the children in the sample were still at school. The one other child of school age was the child who had died. For this reason and, also because this child had actually been transferred to a school outside the sample area, he has been excluded from the figures relating to education only. However, the circumstances of the transfer are relevant to the present study. The parents had been dissatisfied with the provision for their child within the county. They felt that he was being kept clean and tidy at school but was not being mentally stretched. They believed that most of the children were less-able than their son and that the teachers had to spend a lot of time controlling disruptive or distracting behaviour. In addition, they said that he could "speak" whereas the others couldn't. They had had a "fight" with the Education Authority which lasted for three years but they believed that they were acting in their childs best interests and that what they were asking for was "no more than what should be provided by our society in the twentieth century". They said they had been very satisfied

with the results of the move.

All but one of the six schools which now existed (one had been closed) had had new headteachers between 1977 and 1982. The great majority of the parents thought that there was very good contact between home and school, both quantitatively and qualitatively, but a number said that this had improved considerably during the last five years. They saw this greater openness as a direct result of the new headteacher's attitude to parents. Parents with children at each of the six schools involved said that they were welcome to visit the school at any time.

Forms of contact between home and school included letters, telephone calls, messages sent via taxi-drivers, a "home/school book"* in which teachers and parents could exchange information and comments, concerts and other special events at school as well as Open days, evenings or even weeks or fortnights when parental visits were particularly encouraged. Three of the schools had some kind of official Association for parents and teachers; in one case this was said to have "dwindled" but some of the parents were trying to get it going again. A fourth school had recently begun to arrange occasional evening meetings for parents on an informal basis. Only one couple who had attended such meetings expressed an uncertainty about their usefulness. They felt

*Two families commented that their child now had a teacher who did not use the home/school book. They missed this form of contact, particularly in one case where the mother had not been able to go to the school so often since the birth of her third child. Such comments highlight the importance of the parents of this form of regular contact.

that there was too much emphasis on fund-raising and not enough on educational issues. It is important to note that, as in the 1977 sample, there were a considerable number of parents who could never attend evening meetings, either because of transportation problems or, particularly in the case of single parents, because they felt unable to leave their child. Another form of contact mentioned by parents from two schools was the arrangement of social evenings for children by parents and teachers.

The parents of 4 of the children said they would have liked more contact with the school than was presently available. Three of these families were from the same school. In the fourth case, the parents were concerned about the quality as well as the amount of contact. They said that, in their experience, parents and teachers did not communicate effectively with each other. These parents were the only ones to give a negative answer when asked whether they felt the teachers took notice of what they had to say about their child, they said that the teachers listened but gave the impression that they were the experts and therefore knew best. The father commented that in the area in which they lived authority figures like doctors and teachers had traditionally been looked up to to the extent that no-one would dream of questioning their opinions and there is therefore often resistance when someone dares to disagree with them. While this was an isolated opinion, it may be that parents' perceptions of the relative expertise of parents and teachers leads them to devalue the importance of their own view of their child's needs.

As in the 1977 study, there were regional differences in the parents' perceptions of home/school contact. The present study, however, indicates a definite improvement in parental satisfaction with the amount and quality of the contact between parents and teachers.

Nine of the families said that they had been given some guidance during the last five years about how to help at home with their child's learning. In 4 cases this had come from teachers and speech therapists, in 4 cases from teachers only and in one case from a speech therapist only. Of the 15 families who said they had not received any such guidance, 9 said they would have welcomed it. Those who thought such help would not be useful thought either that their child would not do things for them at home or that it might have helped when the child was younger but not now. One couple who felt strongly that this sort of guidance would be helpful said that they had been trying to get help of this nature for years, but without success. They would like parents to be able to spend time at the school, possibly for a regular period of half a hour or more a week, in order to learn what they could do to help. They thought there were other parents who shared this view.

Only 3 of the children in the sample had had a home teacher during the last five years. In each case this was when the child was unable to attend school. Two families had been very pleased with this provision and in the third case the parents said that it had not been for long enough for them to make

any comment. One parent thought that having a home teacher could be useful in that parents would be able to watch and see what to do. Three others thought that extra tuition would be helpful though 2 of these only wanted help with speech. The majority of the parents thought that the child wouldn't concentrate at home and needed to mix with other children though several thought that home tuition might have been helpful in the early years, especially before their child started school.

Only 2 families had paid for private teaching for their child in the last five years. In both cases this was for help with speech because speech therapy was not being provided in school. One of these children was not having speech therapy in school because her need was not considered to be as desperate as that of many others. These parents paid a speech therapist for six months. It was expensive but they considered that it was worth it because their child seemed to benefit from help and the parents now felt able to help her themselves. The other family had tried elocution lessons for a short time as a substitute for speech therapy but this was not successful. Another couple had tried unsuccessfully to obtain the services of a speech therapist.

Table 24 shows what the parents thought their child had gained most from attending school.

Table 24: Parents' views of what their child had gained most from being at school

(Note that some parents gave more than one answer)

	Number
company/ability to mix with other children	9
social skills/socially acceptable behaviour	7
confidence	6
independence	4
contentment/happiness	3
concentration	3
speech/communication	2
general knowledge	2
nothing/very little	2
improved coordination	1
learned to spell, count, tell time	1
learned to sing	1

Of the 24 families with children attending schools in the sample area, 20 said they were generally satisfied with the present arrangements for their child's education. This figure obviously represents varying degrees of satisfaction and half of these families had suggestions to make for improvements in the provision. A number of parents said that they had become satisfied because the situation had improved a great deal. Amongst improvements mentioned were "vastly improved" teaching methods and greater provision of speech therapy. One parent said that the need for more speech therapy had been her "pet thing" for the last six or seven years. There were some parents who thought that the improvements had probably come

too late for their own children to benefit much from them. There were numerous favourable comments about the schools including:

"We can't speak highly enough of the school and the staff"

"They're like mothers to them"

"They really work hard for the children. They do marvellous things with them. He loves it there".

There were 4 families who said they were not satisfied with the present provision but again, this did not imply total dissatisfaction. For example, none of the parents thought their children were unhappy at school or were displeased with the way they were cared for. Most of the comments from this group have been included in the list of changes which the parents thought were desirable but there were a few points made by these parents which can more appropriately be recorded separately. One parent considered that her child's school was fine for those children who could walk and talk but that there wasn't a lot of learning in the special care unit. Another was not happy with the whole idea of "special" schools for children with learning problems and believed that they mainly served to give a break to the parents and that the only progress the children made was the outcome of natural development. One couple said that they had hoped for greater improvement under the auspic es of the education service than had been realised. In view of the requirements of the 1981 Education Act for the involvement of parents in the ascertainment of special educational needs

it is interesting to note the extent to which these parents were unhappy about the arrangements for assessment. They had asked to attend the assessment meetings relevant to their seventeen year-old son which were held at the school every six months. Their request was refused* and they were told that the parents were represented by social services personnel. However, the family did not have any regular visits from a social worker. There were teachers at the meeting but apparently not their son's teacher and the local paediatrician was not involved although he knew the child and the family well. One parent felt that the apparent lack of goals was a problem for the parents themselves. "There don't seem to be any important stages for these children..... Parents also need incentives and encouragement - something they're working on together". It may be that if teachers and parents could work together on goal-definition and goal-achievement the contact between them would be both more meaningful and more productive. Several parents were concerned because they believed that their children picked up bad habits at school.

Table 24 shows the changes in educational provision considered desirable by the parents. (Note that some parents suggested more than one possible change).

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*Two families with younger children at one of the other schools mentioned being invited to attend meetings where they could discuss their child's progress with representatives from the three services. (One family said they had enquired about the meetings and then were invited). They had found these discussions very helpful.

Table 26: Changes in education desired by parents

	Number
none	10
more speech therapy	6
more teaching of domestic skills and crafts	4
caravan or kitchen fitted out for domestic/ social skills practice	
better staff/pupil ratio and more individual attention	3
more physiotherapy	3
some sort of integration with 'normal' children	3
more able children grouped together	2
information given to parents about assessment of child's potential	2
more social skills teaching	2
more use of television as a teaching medium	1
more teaching of reading and writing	1
all teachers should have qualification in special education	1
more toilet training	1
more effort expected of children	1
more swimming and the provision of a swimming pool at school	1

It is possibly important to note that more speech therapy is the most frequently mentioned desired change in both studies. It might also be that some of the changes considered desirable by the present sample, such as more teaching of domestic skills, reflect the increased age of the children.

POST-SCHOOL PROVISION

Fifteen of the young people in the sample had left school. Thirteen of these attended an Adult Training Centre (A.T.C.) though one went only two or three days a week. Four of these young people were in the Special Needs Unit of an A.T.C. One other young person had a place at A.T.C. but had been at home unwell for several months and was in hospital at the time of the interview. There was some uncertainty as to whether she would be returning to the A.T.C., though her place was being held open for her.

One young person spent all his time at home because apparently there was no vacancy for him at his local A.T.C. when he left school at the age of sixteen. His mother said that they had been told that if he stayed on at school there wouldn't have been room for the younger ones to start. She had felt it would be a pity for these young children if her son's staying on had prevented them from starting school. They told her that he would be able to go to the A.T.C. when a place became available but at the time of the interview he had been at home for about two years. Their social worker had been very supportive and had made considerable efforts to get him a place at an A.T.C. These parents were now completely tied. They had no car and their son was confined to a wheelchair so they could not go anywhere which was not within wheelchair-pushing distance. Neither parent was in good health. The father had received an invalidity pension since having a heart attack seven years ago and the mother had had a stroke

four years ago from which she had made a slow recovery. The mother commented that while her son was no trouble it was a bit of a strain having him at home all the time and she thought it must be boring for him. (Another young person in the sample from the same district and of exactly the same age remained at school until the age of seventeen and then was placed in the Special Needs Unit of the local A.T.C.).

Three of the young people who attended an A.T.C. had had to wait a considerable time for a place after leaving school. In the first case, however, the young person concerned could have stayed longer at school but she apparently wanted to leave when she was sixteen. She was at home for a year before a place became available at the A.T.C. Another left school at sixteen and was at home for five months. Her mother would have liked her to stay longer at school. ("I don't think education should stop with children like this"). The third young person was at home for nearly a year after leaving school at the age of seventeen. According to the parents, their daughter "got reported" for being at school over age. (While it is possible that a complaint was made by someone who thought that children had to leave school at sixteen, it is hard to imagine any action on the part of the Education Authority being consequent on such a complaint, in view of children's rights to education until the age of nineteen). The parents were told that there was nowhere for their daughter to go. She became very hard to handle at this stage (having bouts of screaming, for example) because she couldn't understand

why she couldn't go to school. The parents wrote to the local authority to protest about the lack of provision and were visited by social workers who suggested that they should consider residential care because of their daughter's difficult behaviour. This was not what the parents wanted and discussions followed about ways of helping them to cope at home. This resulted in a grant being made towards a house extension. In the meantime the parents were invited to a meeting with representatives of the Social, Education and Health services. They said that they had expressed the view that it was cruel to give their child "a taste of outside life" and then nothing else. The eventual result was that, after their daughter had been at home for almost a year, a place was "found" for her two days a week and gradually increased. There was no further difficulty with her behaviour. These three young people had left school four or five years before the present study took place. In a fourth case where the young person had left school five years previously at the age of seventeen, the parents would have liked him to have stayed longer.

The difference in outcome between the two main situations in which there was apparently no A.T.C. place available is perhaps illustrative of the plight of some parents who are either unable or unwilling to "fight" on behalf of their children. It also suggests that individual workers within the support services may be equally powerless in certain situations. In the case concerned, the family's social worker had apparently done everything possible in terms of support

and assistance (the mother could not speak too highly of her) and yet she had been unable to obtain a place at A.T.C. for the young person.

Reid (1979, p.44) notes that there were children in the 1977 sample who were due to leave school in July and whose parents did not know in May what was going to happen to them when they left school. He also said that there was little evidence of concerted family contact concerning vocational training.

In the 1982 sample most of the parents had known for a period ranging from several months to a year that the child would be given an A.T.C. place. In most cases, however, they did not know when a vacancy was likely to arise and many were informed of this only at the last minute.

One couple had a visit from the assistant manager of the A.T.C. to say that their daughter could start on the following Monday. They had never received any written notification. One mother had a letter about a vacancy a week before her daughter started. Another mother had a letter on the day her son should have started. In another case there was some last-minute confusion over the availability of a place. The child had been confused with someone else with the same surname.

However, the majority of the parents considered that they had shared in the decision as to where their child should go

after leaving school. Two families said that the decision had been made by the school but that they had been consulted. One mother said that she had been asked to decide which A.T.C. she would like her daughter to attend. In one case the parents had attended a meeting to discuss their child's future placement and had asked if his transfer to A.T.C. could be deferred because they felt that he would need time to adjust to the change. It was agreed that he should attend for one day a week for a few months. The mother considered that their experience showed that "if you go and give your side they do help you". Two families pointed out that there was no real choice of provision and that they were grateful to have a place at all. Two families said that they had taken the initiative and had visited the school to ask if their child's name could be put down for the A.T.C. They were worried that if they didn't do something there might not have been a place available. In only once case the parent said that the decision had been made without consulting her and also in one case the decision was said to be taken by the parent alone.

For the majority of the young people, the transfer from school to A.T.C. was accomplished smoothly. A number of parents said that their worries about this had proved to be unfounded. Only one parent had noticed any behavioural problem. Her son had had what she described as "a few outbursts" at first but she felt that this was as likely to be connected with his stage of development as with the change from school to A.T.C.

The change had very little effect on family life though several families found that life was a little easier once their handicapped member was at A.T.C. for a full day and there were no school holidays to worry about.

The parents of 10 of the 14 young people who had places at A.T.C.'s said they were satisified with the present provision for them. Many of them spoke enthusiastically about the wide range of activities available for their children to participate in. Typical comments were:

> "The Training Centre is excellent. She enjoys it and it gives her an interest outside the house"

> "It's a happy environment and she's well-cared for. It couldn't be much better as far as T. is concerned".

> "They're teaching him homecraft in case he should ever go in flats with others. I think this is good".

Several parents of the more severely disabled young people gave the impression that they didn't see the A.T.C. as a learning situation as far as their particular child was concerned or else that they saw learning in terms of formalized learning. "She isn't going to learn any more"; "Nothing more can be done for him".

The other 4 families stressed that they were grateful for the provision for their children and that it was with

reluctance that they admitted to not being entirely satisfied. These cases are reported individually because of the small numbers involved.

One couple initially said that they were satisfied with the provision but their further comments revealed that they were only satisfied in that they believed that the A.T.C. staff had done all they could for their child. They considered that the Training Centre did not really meet her needs. She had become bored with jobs like putting screws and gift tags in envelopes but her severe physical disability prevented her from coping with more difficult tasks. This young person had developed a strong interest in one particular pop group since leaving school. Her parents had fostered this interest by providing books and other materials relating to the group and her reading and writing had improved sufficiently for her to carry on a correspondence with other members of the fan club. This had indicated to her parents that she could learn if she was sufficiently interested. They also felt that some of the life-skills teaching at the A.T.C. were unsuitable and unnecessary for their daughter. For example, she was being taught to use a conventional telephone with a dial which she couldn't manage. She had a press-button phone at home and often rang her friends.

One mother thought that the young people ought to have more in the way of education. She would like her son to have gone on with reading after leaving school. She would like

them to do courses in skills like gardening and domestic science rather than just packing things or folding cigarette papers but she believed that they hadn't got staff with the appropriate skills to run these courses.

The parents of a non-ambulant young woman thought that not enough was done for the young people who were confined to wheelchairs because those who are mobile demand more attention. They suggested that they could be read to or shown slides. They also felt that their daughter could learn more. The mother said "I think they look at her and say 'She's badly handicapped - her mind doesn't need jogging along'". They were also unhappy about the fact that her nappy was never changed at the Training Centre. They also missed the sort of feedback which they had from the school, "They don't really talk to us about her". The parents had got the impression that the staff regarded their daughter as a problem while they considered that she hadn't got a difficult disposition.

Another mother thought that there was "more production going on than learning". She felt strongly that education shouldn't stop with children like her daughter particularly because "It's now that she seems to be aware". This young person had been having an hour's reading lesson twice a week at the centre and seemed to be getting on well. She was apparently very keen to learn. When the person on the project was moved to another section to gain experience the reading lessons stopped. The mother said she did not want to criticize

because she knew they were short-staffed and very busy but she felt that it was a great pity to start on a project and then not continue with it. She would also like to see more opportunities for integration with other members of the community and she considered that a speech therapist was needed at the Centre.

HOSPITAL MEDICAL SERVICE

Table 26 shows the frequency with which the children in the two samples visited a hospital to see a medical specialist.

Table 26: Frequency of children's visits to hospital to see a medical specialist at the time of the two surveys

Frequency	1977		1982	
	No.	%	No.	%
daily	1	0.66%	-	-
weekly	1	0.66%	1	2.5%
fortnightly	1	0.66%	1	2.5%
monthly	7	6.5%	2	5%
every 2 months	-	-	3	7.5%
every 3 months	20	17%	5	12.5%
every 6 months	30	25%	6	15%
annually	17	14%	2	5%
Total	77	64.5%	20	50%

In addition, 2 families in the 1982 sample who did not take their children for regular visits said they attended the hospital whenever they felt it to be necessary. In the 1977 sample, a further 40 children were said to visit a medical specialist "infrequently". This difference presumably means that most of the children who saw a medical specialist less than once a year in 1977 did not need to visit one at all

in 1982.

Visits to a Paediatrician

Sixteen of the children (40%) made visits to a paediatrician. The comments made by the parents indicated that the close relationship which Reid noted between the paediatrician and the family of the handicapped child was still in existence and had probably strengthened over the years. Typical comments were:

> "He's been marvellous - like an old friend. We can't speak too highly of him".
>
> "She's really good - so very nice to talk to"
>
> "Very good, very understanding. He was one of the nicest when she was ill".

In addition most of the parents said that they had been told to telephone the hospital anytime if they were worried about their child.

Specific help given by the paediatrician included: information about help available, advice on toys to assist development, arrangements for appointment with a child psychologist, contact with school and social services on parents' behalf. A number of parents also said that the paediatrician had shown concern about the needs of the whole family. For example, one mother said that the paediatrician was very understanding when she was going through a divorce and suggested that her child went into short-term care so that she could have a break. Another mother said that the

paediatrician was very concerned about her health and her need for a holiday. One mother said of her visits to the hospital to see the paediatrician, "It's the only place I could go for advice".

The parents of 12 of the 16 children who visited a paediatrician said that the explanations given were to their satisfaction. Of the parents of the other 4 children only one was very dissatisfied. In one case the adequacy of explanations given was said to vary, depending on which doctor was seen. In another case the problem had only arisen since a new paediatrician had taken over and in this case the parent thought the problem would be overcome anyway once he got to know his patients. The third parent's complaint was that, "They never tell you everything..... only what they want you to know..... what they think you can take in". She was happy with the quality of the explanations she did receive and said that the paediatrician always tried to explain in layman's terms and didn't "baffle with big words".

The family that was very dissatisfied with the explanations they received from their paediatrician was the only family that thought the paediatrician did not take notice of what they said about their child, though there was one couple who said that their new paediatrician listened to their viewpoint and acted on it whereas the previous one had not done so.

There were 2 families whose children were no longer in the care of a paediatrician who expressed their dissatisfaction with the treatment which they had received in the past. These cases are recorded because of their similarity and because they relate to local hospitals in two different districts. Both children were epileptic but did not see epilepsy specialists. (One of the parents commented that there was no epilepsy specialist at their local hospital). In one case the child was being given an increasingly large daily dose of drugs to control her epilepsy. She had become so ill that the parents were 'toncerned for her life". The paediatrician had originally told the parents that five or six a day of the tablets he was giving her would be the limit, so when he prescribed nine they asked if they could take her to an epilepsy specialist at another hospital because they no longer had any confidence in him. (The father admitted that his anger had induced him to make a mildly abusive remark to the paediatrician). At first their wish to transfer to another hospital was resisted but when the parents said they would have to borrow money and go privately if necessary, the arrangements were made for the transfer. The epilepsy specialist reduced the dose of drugs to one third of the child's daily intake and in three months the parents said there was a vast change in her. These parents emphasized that the point they wanted to make was that the paediatrician could not be expected "to know about everything" and that they believed that children with epilepsy should see a specialist much earlier than seems to be the normal practice.

The other child was transferred to the care of an epilepsy specialist when he left school at the age of sixteen. His daily dosage of drugs was also reduced to a third of the amount previously prescribed and he was said to be a great deal better. Before this, according to the mother, he often "couldn't lift his head". This mother also said that the treatment was now being explained to her. "The other doctors never used to tell me nothing".

Visits to a Medical Specialist

Twelve of the children (30%) visited a specialist other than a paediatrician in relation to one or more of their physical conditions or handicaps. In 2 cases the child saw more than one specialist. In some cases, such as the 2 referred to in the previous section, the children had not been under the care of a specialist for a long period. While there was not the same expectation or evidence of the specialists involving themselves with the family in the way that many of the paediatricians did, it was clear that in a number of cases, particularly where the family made many visits to see a specialist, a good relationship had developed. This was illustrated by one mother who said, "We've had so many problems with J. over the years that we have built up quite a relationship". Another mother said of the specialists she saw, "They have been absolutely marvellous". As with the paediatrician, a number of the parents said that they could telephone the specialist at any time if they were worried about their child.

The parents of 7 of these 12 children were satisfied with the explanations they received. One mother said, "They'll always answer my questions and explain". In 3 of the 5 cases where the parents were not satisfied, the adequacy of the explanations was said to vary with the doctor seen. One mother of a nineteen-year-old girl, for example, had seen a different eye specialist at her last visit who had mentioned that her daughter had cataracts. When the mother expressed surprise the doctor told her that her daughter must have been born with them and that she should have been told about it. In the other 2 cases, one parent said that the specialist did not offer explanations unless she asked and another that parents were not always given the full picture.

A comment from one mother who expressed satisfaction with the explanations she received may have considerable relevance to any consideration of how the situation has changed over the years.

> "I didn't (feel things were explained as much as I would like) in the beginning. I'm a bit more cheeky now. At first you don't like to ask - sometimes you don't want to know. You accept it more as they grow older. Now I want to know every little thing. Perhaps I've learned to talk to them better".

This comment (together with a similar one from another parent) highlights the need to take attitude change into account in assessing any improvements in a situation, particularly one which involves relationships.

There were 2 families who felt that the specialist did not take notice of what they had to say about their child. One mother, who had tried to convince the specialist that her daughter was "turning badly on her feet", said "I see her every day. He only sees her every six months".

Visits to a Physiotherapist

Two of the children had regular physiotherapy at a hospital. The mother of one of these said she had "fought" for this years ago and then it was stopped after three or four sessions apparently on the grounds that she was "doing it well at home". Then the provision had been made available to them again three months ago and the mother was delighted with it. "He's wonderful with her. I couldn't wish for more". A third child had been receiving physiotherapy but this was stopped because apparently "no more could be done for him".

Visits to a Dental Hospital

Ten of the children in the sample had regular appointments at a dental hospital out-patient clinic. The parents of all these children were very pleased with the care they received. There was a day set aside periodically for the treatment of mentally handicapped children and there were toys provided to occupy the children while they waited. There were many comments in praise of the staff, including,

"They're very patient with them"

"Nothing is too much trouble"

"They're marvellous with her there.... It's so much easier when people understand".

Admissions to Hospital

Twenty-four of the children had spent some time as hospital in-patients during the last five years. Table 27 shows the number of admissions to hospital in each case. Four of the children who had had one admission to hospital were only there for up to twenty-four hours. One child who had had three spells in hospital was there for one period of eighteen months.

Table 27: Admissions to hospital during the last 5 years

Number of Admissions	Number of Children
1	14
2	4
3	2
4	1
"Frequent"	3
Total	24

The majority of the children were said to have either thoroughly enjoyed being in hospital or had no apparent reaction to it other than slight settling problems in a few cases. Seven of the children were considered to have reacted badly (though in one case this was because the child had taken

poison and the whole experience was very frightening. He had had another period of hospitalisation with no apparent reaction). One child, whose mother was not allowed to stay with him, had apparently cried all night. Another child had been so noisy that he had frightened the other patients and he was discharged at the earliest possible moment. His parents wished that there could be special wards for mentally handicapped children where the parents could stay with them. The child who had had a period of hospitalisation lasting eighteen months was described as having reverted from being "clean and dry" during that time to being "back in nappies" at the time of the interview.

One couple, whose daughter had been admitted to their local hospital after a fall had been very upset by the way she had been treated. They had explained that she was mentally handicapped but she was treated as if she was normal. She had not been washed or taken to the toilet. She came home "in a terrible state" with her gums covered in pus and her face still covered in congealed blood from her fall.

Improvements and Continuing Problems

Nine of the 22 families thought that their visits to hospital had improved during the last five years. Table 28 shows the aspects which they considered to have improved.

Table 28: Parents' perceptions of improvements in hospital visits (some parents named more than one improvement)

Improvement	Number
waiting time less	4
change of doctor	4
parents accept situation more and can talk to doctors more easily	2
child transferred to hospital nearer home	1
specialist now sees child downstairs (Mother has difficulty in carrying her upstairs due to back trouble and breathlessness)	1

The appointments system and the parents' relationship with, and confidence in, the doctor seemed to dominate their perceptions of the hospital visits, but it is interesting that 2 of the parents attributed much of the improvement to a change in their own attitudes. One of them said,

> "Years ago I felt that visits were a waste of time and nobody helped. But I was probably finding my way with everyone and probably hadn't really accepted that C. was handicapped. I was looking for a miracle cure. It must be the accepting that helps.... I can talk to them more easily now - I'm older and wiser... I think a lot depends on how you are yourself with people as to how they treat you".

As well as improvements, however, there were continuing problems. The period of waiting to see the doctor was still a problem for some families. The parents' estimates of their average waiting time is shown in Table 29.

Table 29: Parents' estimates of average waiting time

Average waiting time	Number
"not at all"	4
up to 15 mins or "a very short time"	5
up to 1 hour	6
up to 2 hours	2
2 hours or more	2
varies a lot	3
Total	22

This table suggests that in most cases efforts were made to keep the waiting time to a minimum. One mother said of the paediatrician, "Dr. J. never keeps these children waiting". A number of parents said that they had learned to "play the system" over the years and that they now knew the most advantageous times both to book an appointment and to arrive at the hospital in order to minimize the waiting period. (one mother said that it was therefore difficult to know whether the system had improved or whether she was just coping with it better).

One mother described the appointments system, whereby, for example, four people may be given the same appointment time, as "crackers". She commented that, in her experience, the doctors were never late and that it was the organisation which was at fault. There had been times when she had felt like going home because her daughter was so difficult to cope with. She pointed out that a "gruelling" waiting time could

adversely affect the usefulness of the consultation because, "By the time you get in there you've forgotten half of what you wanted to say". (This mother was told at her last visit that her child would be fitted in quickly in future). Five of the mothers said that they had some problems with keeping their child occupied. One of these said that if the child got upset and cried she was usually fitted in quickly. Two mothers said they would like more play facilities for the children while they waited. One of these said she could not help comparing the facilities of her local hospital with those of the Great Ormond Street Hospital out-patient clinic, where the play provision was so good that "the children probably don't want to leave the waiting-room".

Reid (1979, p.29) notes that many parents complained about the problems of seeing different doctors at each visit. The great majority of the parents in the 1982 sample saw the same doctor at each visit and a number of them said how important this was to them. One mother said, "The times you don't see him you feel let down". There were 7 families who did not normally see the same doctor but several of these said that they could make a request to see their consultant. In 3 cases the fact of seeing different doctors each time was considered to have caused some problems. One couple believed that seeing a succession of registrars who did not know the child had led to the neglect of a fairly serious problem.

One family was very dissatisfied with the hospital medical services and although this was an isolated case it is useful as an illustration of some of the factors which can lead to dissatisfaction. They did not see the same doctors on each visit and were asked the same questions each time. "They look at the notes, but yet they don't look at them - they ask you again". The doctors' failure to answer their questions led to a lack of confidence:

> "You ask them things and they don't tell you. I don't think they know".

The apparent lack of attention to their worries was producing even greater anxiety:

> "They definitely don't take notice of what we have to say. He's been getting very bad headaches. If anything happened they'd say 'What were the parents doing?', But we keep on and on and they take no notice..... If they just listened - took notice of what you have to say. You know when there's something wrong with your own child. We had to practically beg them to X-ray his legs, whereas the doctor in casualty knew there was something wrong straight away..... I feel they're not paying sufficient attention to body growth - it should be checked frequently".

It may be that the greatest need in this instance was for someone with time to listen to the parents' worries, to give reassurance where appropriate and to convince them that any necessary action would be taken. It may also be significant that these parents estimated their length of wait as varying from a short time to three to four hours, the latter period being the longest mentioned by any parent. Perhaps even more significantly, their impression was that the time they spent with the doctor was "about two minutes". While this may not be a realistic estimate of time, the sentiment behind it is in contrast to the answers given by those who were satisfied with the hospital visits. For example, several parents gave answers like, "It depends on how she has been and my worries" and, "He never rushes us".

These dissatisfied parents wanted a transfer to another hospital. They had asked if they could have a second opinion but so far this had been refused. (Instances of this nature are noted by Reid (1979, p.29)). However, their Health visitor had offered to try and do something to help.

One mother had considerable problems arranging transport for her son's visit to the dental hospital and therefore failed to keep some of his appointments. She had approached the social services but apparently they were unable to help. Many of the fathers had to take time off work to drive the car. (One father said that a lot of his annual leave was taken up with hospital visits). One father found that parking sufficiently close to the hospital entrance was a problem. He considered that more parking facilities were needed for the severely disabled. In 2 cases the only reported problem was waiting around for ambulances after the appointment. This could be for as long as two hours.

While it is difficult to make comparisions with the 1977 sample in some aspects of hospital care, the indications are of a greater degree of satisfaction with hospital visits in the 1982 sample, though there were still important areas where improvement was seen as desirable.

CARE IN THE COMMUNITY

The General Medical Practitioner (G.P.)

In 31 cases (77.5%) the parents said that their handicapped child either never or very seldom saw their G.P. Some of these parents considered that their child's medical care had been completely taken over by the hospital and was out of the G.P.'s hands. They explained that they would always contact the hospital if their child had any health problem and that this was not in any sense a reflection on their G.P.

Other parents were resentful that their G.P. had shown little or no interest in their handicapped child. They made such remarks as:

> "They never ask how she is"
>
> "He hasn't really taken any interest"
>
> "His G.P. has never enquired about him in 20 years".

One parent said, "The doctor didn't even know he was on his list". Another recounted that when one of the doctors from the practice had visited her child at home he had begun to put his questions to the child until the mother intervened and said "she doesn't understand". "Why?" the doctor had asked. He had apparently forgotten that she was mentally handicapped.

A number of parents regretted the change from 'family

doctors' to large group practices and health centres. Their feelings are illustrated by the following comments:

> "I don't know who my own doctor is. It's not like it used to be - a sort of consortium. I haven't got a family doctor, more's the pity. Someone you can talk to, isn't it?"

> "With the old doctor they know the family - its not the same with the Health Centre".

Two families considered their G.P. to be unhelpful (as opposed to merely lacking in interest). In one case the doctor had refused to come for two days when the handicapped child had been ill. The mother said, "I wouldn't go to him even if I had a problem". The other mother considered that her doctor had a very difficult attitude to her. He had refused to sign the form for her son to receive the invalidity allowance. "I get low over these things".

Only 10 of the families visited the surgery with their handicapped child. In many cases the parents had been told by their G.P. not to bring their children to the surgery but never to hesitate to call them out. Of the families who took their children to the surgery, 5 had some problems with their children when they were waiting to see the doctor. One mother said "They've never allowed her to wait - I think that's marvellous".

All but one of the families said that the G.P. was happy to visit the child at home though in 2 cases the parent said that one doctor in the practice had been "difficult" about

coming and one mother said she had never asked for a home visit.

There were some parents who considered that the G.P. showed a great deal of interest in the needs of the whole family. One mother said that the doctor made a point of giving her a thorough check-up twice a year. Others, however, said they had not experienced this concern and 2 mothers complained that whenever they mentioned their own problems they were just given tranquilizers.

Some parents considered that the quality of care varied with the doctor seen. Two parents said that one of the two doctors in the practice was always willing to listen and to show an interest in the child whereas the other always gave the impression of being 'too busy'. In a number of cases the parents said that a change of G.P. had brought about a considerable change in the situation.

A number of the parents had nothing but praise for their G.P. and it is interesting to note that, despite the small percentage of children who saw their G.P. regularly, more parents said they would turn to their G.P. for help than to any other professional. Typical comments were:

"He's been a wonderful doctor"

"They have always made you feel as if she was the only patient on the books"

"Nothing is too much trouble. We've been told to 'phone if we have any worries - day or night".

Professional Visits to the Home

Twenty-six of the families in the sample (65%) said that they had visits to their home in connection with their child's disability while 14 families said that they did not receive such visits. However, a number of the parents who said that they did not have visits went on to mention occasional visits brought about by particular situations and it was apparent that such visits mainly represented crisis care. Others had had visits in the past and some of the parents had concluded that these had been discontinued because their child was "well looked-after". One mother who said that she received no professional visits to the home, had 'Home Care Assistants' provided by the social services to help with bathing and to provide short periods of daytime care in the school holidays while the mother went shopping.

It is interesting to note that 20 of the 25 families with children still at school were said to have professional visits to their home compared with only 6 of the 15 families whose children had left school. While no conclusions can be drawn when the numbers involved are so small, the apparent lack of professional support to families with older children is a matter for concern and one which may need further investigation.

There was also some evidence of differences between districts in amount of professional support received.

Again, while no conclusions can be drawn because some districts were only represented by a very small number of families, this is a matter which may need to be given professional consideration.

Table 30 shows which professionals were reported as visiting the families other than in a crisis situation or following a specific request from the parents.

Table 30: Professional Visits to the Homes

	No.of families visited	% of families visited
social worker	15	37.5%
toy librarian	15	37.5%
health visitor	10	25%
community nurse	7	17.5%
psychologist	2	5%

Some of the families received visits from more than one professional, as is shown in Table 31.

Table 31: Distribution of Professional Visits

No.of different professionals who visit the home	No.of families	% of families
0	14	35%
1	12	30%
2	6	15%
3	7	17.5%
4	1	2.5%

There seemed to be no evidence of a relationship between

degree of need and amount of professional support received. Some families with very difficult home circumstances apparently received no visits at all.

The bitterness or anger felt by some parents about the lack of professional support is illustrated by the following comments:

> "This is our one great grievance"
>
> "It is my one complaint - you never get any back-up. No-one ever comes to see you or anything...Perhaps if I do collapse on the floor perhaps something will be done then....I really do feel there is a break-down in support".
>
> "There's never anyone to advise you about anything".

Several parents thought that their children were, or had been, unknown to the appropriate authorities. One couple said that they had been told five years previously that a social worker would come, but no-one had. The father said, "I don't think they know he exists". One mother said that the health visitor who came after the birth of her youngest child had not known about her handicapped child and had been unable to find any records relating to her. Another mother said she began to have visits from health visitors and social workers after one of her handicapped twins had been seriously ill in hospital. They were reported to have said that they didn't come before because they didn't know about the twins. "I suppose it's because I never troubled anybody".

As noted earlier, a few parents said that they felt that their child was their responsibility and that for this reason they did not

ask for or expect help from sources outside the family. Some parents also expressed the view that more was done for people who did not help themselves.

A number of parents said they knew they could always make contact with the appropriate professional if a problem arose. Some were happy with this arrangement. "If I need help I'll seek it out". Others, however, did not find this satisfactory: "But you don't ring these people. It's so much better if they come to you". Greater attempts to discover which parents would like regular visits (as had been done in a few cases) may therefore increase efficiency.

Some parents believed that social workers no longer made routine visits. One said, "They're so over-stretched that they only come if you're desperate and call on them". Another said she had not had a visit for ten years. "They only come if you're in distress and send for them..... In an emergency most people will get help. It's continuity that's a problem. It would be nice to have a friendly visit now and then but you can't ask a welfare officer to come and chat the way you're chatting". In relation to all professionals who visit the home, parents found occasional or very irregular visiting to be unsatisfactory.

A number of parents said that they had become used to coping without support but expressed concern for other parents, particularly those of younger children, because they felt that it was in the early years that they had felt most in need of

support. One father said,

> "I can imagine there would be a lot of people who would find it extremely difficult and if our experience is typical of there being no offers of help (in the sense of advice) then it could prove unbearable, I should imagine".

The great majority of the parents found the professional visits useful, though it was sometimes difficult for them to define the nature of their contribution.

Some families said they had found their social worker mainly useful for the provision of aids and for making essential arrangements such as for short-term care. Others saw the social worker in a counselling role but clearly much depended on the individual social worker and the relationship between social worker and client. One mother, for example, described her social worker as "someone you couldn't really talk to" whereas others could not speak highly enough of their social worker. One said, "she's great. She's only a young person but she's very understanding - just like having a good friend".

The service provided by the toy librarian was well received by the parents and the great majority of them found it extremely useful. It was clear from many comments, however, that the toy librarian was seen as fulfilling a wider role than merely providing the toy service. One parent described her as "More of a social worker - the best help of all". Many parents had found her to be a very useful source of information. She had encouraged some to apply for allowances and one couple said she had even brought house details when she knew that they were trying to move.

One mother said that the toy librarian had been her "only source of advice and help in the early years".

Reid (1979, p.52) noted that the majority of families visited by a health visitor only found those visits useful in a general way. The same conclusion could be drawn from the comments of parents in the present study relating to both the health visitor and the community nurse but it may be that the role of these professionals in relation to the families of handicapped children is both difficult to define and not easily understood by the parents. Many parents spoke highly of the help given by both health visitors and community nurses, some of whom seemed to fulfil a counselling role. One mother described the community nurse, of eighteen months standing in the area, as "marvellous".

The 2 families visited by a psychologist had both found these visits useful. In one case the psychologist had been coming, as part of a research project, since the handicapped young person was a baby and had given useful advice over the years.

One of the continuing problems for parents was the fast turn-over of some professional personnel, especially social workers. Parents would begin to build up a relationship with a social worker who would then leave or be moved to another district. In a number of cases the parents had received no further visits even though some of them had had letters

telling them who their new social worker was.

The increased number of professionals with a knowledge of mental handicap was warmly welcomed by the parents. One family, now visited by both a specialist social worker and a community nurse from the district unit concerned with mental handicap, considered the present situation to be "a great improvement". They said that their previous social worker had known nothing about mental handicap and that her attitude had been "unsatisfactory" to the extent that the father "couldn't stay in the room" when she was there.

The parents were asked whether there was anyone (or anyone else) from whom they would welcome visits at home. Twenty-one families (52.5%) said that they would not wish to receive further visits. In some cases this was because they considered that they were already receiving sufficient visits; in other cases the reason was that they felt they had managed without such visits for so long that they could go on coping without them; in a few cases they did not want visits because they felt resentful about the lack of professional support: "I feel quite bitter now. I don't want them now". In 2 cases the question was not applicable, while 17 families (42.5%) said they would welcome professional visits (or additional visits) to their homes. Table 32 shows from whom this last group would welcome visits. In 2 cases the parents gave more than one answer.

Table 32: Who the parents would like to visit them at home

social worker	11
anyone who can help	3
speech therapists	2
general practitioner	1
health visitor	1
don't know (because don't know who *should* call)	1

This suggests that the main need felt by the parents, in the way of professional support in the community, was for more visits from social workers.

Table 33 shows who the parents said they would turn to for general help or advice. Some parents gave more than one answer and some husbands and wives gave different answers: each of these was recorded.

Table 33: Person the parents would turn to for general help or advice

	No.of parents
general practitioner	9
'don't know' or 'there isn't anybody'	9
social worker	7
friend or neighbour	7
relative	5
paediatrician	4
psychologist	3
community nurse	3
would depend on nature of problem	3
health visitor	1
headteacher	1
teacher	1
staff of adult training centre	1
toy librarian	1
clergyman	1
voluntary organisation	1
other parent of a handicapped child	1
'boss' at place of work	1
colleagues at work	1
solve own problems as a family	1

A comparison between Table 33 and Reid (1979, p.48 Table 3.1) suggest that the General Practitioner remains the professional to whom parents are most likely to turn for help or advice. In the 1982 survey more parents said they would turn to the social worker than to the paediatrician, a reversal of the situation in 1977, but this is not surprising given the increased age of the sample.

School Holiday Provision

Of the 24 families with children at school, 13 found that the school holidays presented some problems. Several parents said that they "dreaded" the holidays. In particular, the

mothers were "tied" to the house (one described it as being "like a prisoner") and shopping was often a problem. Some parents found it difficult to keep their children occupied at home.

A number of the children had hostel care for a fortnight during the summer holiday and this break was much appreciated by the parents. There had been increased short-term care provision during the last five years and there was no evidence that it was difficult for parents to obtain such care for their children as had been found in the original study. There were, however, still some parents who said they did not know what was available to them. One mother was concerned that this provision was not sufficiently local. Some parents who had been offered respite care did not like the idea of sending their children to a hostel.

There were holiday playschemes in some districts, usually run by Gateway in conjunction with the Education and Social Services Departments. It was evident that these schemes fulfilled a great need and some mothers said they only wished they could last longer. One mother described the playscheme as a "Godsend". These projects could not usually cater for the most severely disabled children however, which meant that some of the families most in need of help could not benefit from them. One mother said that her daughter did not cope well with the playscheme because there was "too much noise and activity" and she got "upset and frightened". There were a few families who did not

want their children to attend the playschemes. In particular, several fathers were against this because they wanted their handicapped children to mix with 'normal' children in the school holidays. Some parents in districts with no playscheme thought that this sort of project would be helpful and several were already involved in attempts to set these up.

Other forms of help which parents said they would appreciate in the school holidays were shopping, cleaning and someone to look after or take out their child for short periods. In one district Home Care Assistants from the Social Services De partment would baby-sit for two hours a week while the mother went shopping.

Information about Services

Only 4 families (10%) said that they had had all the forms of help explained to them available. Others, however, had gradually pieced information together from a number of sources. For many parents, the lack of information was the worst problem of all. The following comments were typical:

"If you don't find out for yourself they never tell you"

"Really speaking, I don't know what I'm entitled to"

"Anything we've found out is by chance or word or mouth. We've never been told anything about anything".

"The only way we find out anything is if we pick up the telephone or if we knock at somebody's door. No-one ev er comes to us".

One mother, who said that she'd had to "fight for everything all the time", considered that "they don't tell you what's available because they can't afford to, financially." Several parents

complained that, not only did no-one come to them with information, but there was nowhere they could go to find out what was available to them.

The parents' sources of information included the media, books, friends, other parents of handicapped children and voluntary organisations. In one district parents had been invited to a meeting at the local Adult Training Centre which was attended by representatives of the three services and at which information was given and parents' questions were answered. This meeting had apparently been initiated by the local branch of one of the voluntary organisations (Mencap). The parents who had attended this meeting considered it to have been very informative and it was hoped that it might become a regular event. Some parents said that the specialist social workers had given more information than generic social workers. In one district a specialist social worker had arranged meetings for parents at which information was given. The voluntary organisation Mencap now had a welfare officer in the area who visited parents (mainly 'new' parents) with information. A list of benefits available had been produced by this organisation and sent to parents through the school in at least one district. There was evidence, then, of efforts to improve the transmission of information, though much of the initiative appears to have come from the voluntary organisations.

Coordination of Services

The parents were asked whether they thought the Health,

Social and Education Services worked together any more than they did five years ago. Their answers are shown in Table 34.

Table 34: Parents' perceptions of whether the three services work together more than they did five years ago

yes	9	22.5%
no	14	35%
don't know	17	42.5%

The large number of 'don't knows' seemed to be due to the fact that many parents said they did not have experience of all three services on which to base an answer.

The following comments were made by parents who thought that the services did not work together:

> "It's a pity they don't. They're all separate concerns. You have to answer the same questions again and again".
>
> "They're all going different ways".
>
> "I don't think the right hand knows what the left hand is doing".
>
> "It always seems to me that there's a lot of friction between the services, particularly Education and the Social Services".

One couple thought that while their district Unit was funded jointly, it was administered by the Health Service and close liaison between the services did not seem to be maintained. Another parent had gained the impression that the community

nurse in her district had had opposition from the Social Services because he had taken over their role to some extent. The mother whose handicapped child had died said that she had had "one hundred per cent support from the medical profession". When she was asked about social service support she replied in the negative but added, "But who tells them if someone dies?" This is surely a prime example of lack of coordination between the services and an indication of the need for a 'named person' to provide the link between the family and the services.

On the positive side, the districts Units are in themselves evidence of an attempt to coordinate services for the mentally handicapped and their families. In at least one district parents' meetings had been organised by a specialist social worker in conjunction with the head of the district Unit. Equally holiday playschemes operating in some districts are evidence of cooperation between the statutory services and voluntary bodies. One father spoke of a very recent development which he found very encouraging although it was too early for any results to be apparent. A country-wide organisation called the Association for the Disabled had been set up. It is chaired by a county councillor, the secretary is the Assistant Director of Social Services and the committee is made up of representatives of the voluntary organisations and the social services. As far as this parent was aware, the health and education services were not represented at present but he believed that the coordination of services for which he had been hoping may develop out of this new initiative.

One of the greatest problems in the whole area of community care seems to be that of families 'slipping through the net'. In the apparent continued absence of a 'named person' to provide the link between the families and the services it is pertinent to ask with whom the responsibility lies to see that this does not happen. This is a question to which the services urgently need to turn their collective attention.

The Role of the Voluntary Organisations

65% of the 1982 sample (26 families) said that they belonged to a voluntary organisation compared with only 45%* in 1977, a considerable increase in membership of voluntary organisations in the five year period. About half of the families who belonged to a voluntary organisation said that they did not attend meetings or did not attend them very often. In some cases this was because of transport or baby-sitting problems. A number of the parents said that they did not need as much support from the organisation now as when their children were younger.

There were 8 families in the sample (20%) who said they had never been contacted by a voluntary organisation. Of those who had been contacted, the main reason given for not joining was the difficulty of attending meetings. One mother, however, who had been invited to a meeting, had not felt accepted by the

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*This is the figure given by Reid (1979) on page 46 Table 30. On page 59, however, he says that "43% of the parents did not belong" to a voluntary organisation.

members. "I stood there like a lemon and no-one told me how to join".

Membership of a voluntary organisation was clearly of enormous benefit to many parents. One mother described the experience of joining and meeting other parents as "the best thing that ever happened to me". The most frequently cited ways in which parents considered the voluntary organisation had helped them were by providing moral support and supplying information. Parents also found that the provision of outings had helped the child and the family to socialize: some said that it gave them a social life which they would not otherwise have had. A few families had had financial help from a voluntary society.

There were some parents, however, who felt that these organisations did not meet their needs. One couple no longer belonged because they thought there was too much emphasis on fund-raising and very little on helping parents with problems; another couple had stopped attending because of the predominance of social activities: they were more interested in having help which could contribute to their child's development and a branch founder-member no longer attended because she was "interested in getting things done rather than bun-fights and trips".

The Gateway Clubs (which come under the umbrella of Mencap) were the chief means of contact with their own age-group (out-

side school and Adult Training Centre) for the children in the sample. These clubs appeared to play a very important part in many of the children's lives, providing a full and enjoyable social life, as well as taking some of the strain of constant care from the parents. There were a few children, however, who were so severely disabled that they were unable to join in any activities and there were others who did not attend because their parents were against grouping mentally-handicapped children together for social activities. One mother said she had been invited to take her child to Gateway but she was unable to drive and was apparently out of the district for being collected.

In a number of cases there were not enough children with a particular disability in one district for a viable branch of the appropriate society to be formed and these parents sometimes felt isolated, even if they belonged to a more general voluntary organisation, because they felt that other parents could not fully understand their problems.

In sum, for many parents, belonging to a voluntary organisation helped "in so many ways" while there were others whose needs were not met by such bodies.

Informal Support

Relatives, neighbours and friends

Thirty-two of the families (80%) had relatives living

near them but only 14 of these families (35%) of the sample claimed to have any help from relatives. Several families said of their relatives "they don't bother" but this was not the main reason for lack of help. Many of the parents were at the time of life when their own parents were either no longer alive or were more in need of care than able to provide it. In addition, a number of the parents were now grandparents themselves and their children were therefore occupied with their own young families (some of the married siblings did help with their handicapped brother or sister). Several parents who did not receive help from relatives said that they would certainly receive help if it was needed. Some parents were of the opinion that the "close-knit valley family situation" had broken down.

Sixteen of the families (40%) said that they had help from neighbours. Comments from several of the parents illustrates how important the support of one particular neighbour can become. One mother said, "she's better than any relative. You only need one neighbour like her. I've said to her "If I move, you're moving too!" Another mother said that her former nextdoor neighbour had been "wonderful" and added, "The worst thing that ever happened to me was her moving". Eleven families (27.5%) said that they had help from friends. There was some overlap here, however, because many of the parents said that their closest, and often only, friends were their neighbours. One couple said that they had no friends.

It is interesting to note the considerable number of parents who said they would turn to relatives, friends or neighbours if they needed help or advice (See Table 33). A number of parents who did not have help said that no help was necessary. In fact, several of the mothers were themselves involved with helping elderly relatives or neighbours. The majority, however, said that they had never asked for help because they did not wish to impose on other people. Some of these had had offers of help and others felt sure it would be given if asked for. A few thought that their neighbours were unlikely to be willing to help. Several said that it would be nice to have help offered. Another fairly frequent comment was that most of their neighbours were out at work all day. This emphasizes the increased isolation of mothers who are still 'tied' because of having a handicapped child at the stage when most mothers are enjoying a new freedom.

The Wider Community

A number of the children were well-integrated into their local churches and/or Sunday-schools and the parents were grateful forthe acceptance they found there and for the opportunity of mixing with 'normal' children. (One mother was convinced that her child had learned to speak at Sunday-school because of this contact). In some districts a special service was arranged by the local Mencap branch and held in one of the local churches during Mental Handicap week. One Sunday-school had sent tapes and books when the child was ill, another had "made a big fuss" of the young person on his eighteenth birthday

and one church had given money for a trip to Lourdes. The mother whose child had died had found both her local Anglican and non-conformist churches to be supportive. However, there was no evidence of any regular practical support being given by these churches. Only one parent said they would turn to a clergyman for help or advice although many churches in the area would not have had their own minister.

Two families spoke of the helpfulness of the staff of local shops. In one case, the mother said she only had to telephone and they would deliver anything she needed. Another mother had been told that her daughter could stay at the shop if her mother ever needed to leave her for a short period.

Twenty-one of the 39 mothers (54%) said that they felt lonely or isolated at times compared with 57% of the original sample. These figures suggest that for families with handicapped children feelings of loneliness and isolation decrease very little as the children get older.

The parents were asked whether they thought the International Year of Disabled People (IYDP) had made any difference to people's attitude or made them more willing to help. Their answers are shown in Table 35.

Table 35: Parents' perceptions of whether the IYDP had made any difference to people's attitudes or made them more willing to help

	Number	%
yes	18	45%
no	10	25%
unsure	10	25%
for the year only	2	5%

It should be noted that a negative answer did not necessarily imply that people's attitudes were unhelpful but only that they were unchanged. Some parents, for example, felt that their children had always been accepted in the community where they were born and brought up. Similarly, some parents who were "unsure" felt that attitudes were changing but were not certain that this was attributable to the IYDP: "People's attitudes have definitely changed and being handicapped isn't a dirty word any more. But people were already becoming more aware - it may not be due to the International Year of Disabled People". Some parents had noticed a marked change:

> "The community has accepted our children and welcome them wherever we go. We never used to go out because people used to laugh".

> "It's amazing to think that a few years ago these people were kept out of the public eye. Now they're out in the community just like everyone else".

Others, however, had not found such a change:

"People still ignore her, or stare..... I don't really see much difference in local people's attitudes".

Yet others felt that the apparent change did not go very deep.

"The most people will get involved is putting their hand in their pockets and giving a donation. People's time and understanding and involvement is so much more important".

To end on a positive note, in the words of one father:

"The International Year of Disabled People was just a start. It is up to us to try and build on it".

The parents who thought that the IYDP had been instrumental in changing people's attitudes were asked in what ways they considered it to have helped. Their answers have been categorised in Table 36. Some parents gave answers in more than one category.

Table 36: Parents' perceptions of the improvements brought about by the IYDP

	Number
people are more aware of the problem/ the issue has been brought out into the open	16
more acceptance of the disabled by the general public	8
people have been encouraged to give more generously	4
more being done for the disabled now	3
more integration of handicapped and 'normal' children	2

The Long-Term Future

The one parent whose child was in residential care was very satisfied with the way this had worked out. He had been instrumental in the establishment of a new local authority home in his own district for young people over the age of nineteen who required constant attendance. He considered the facilities and care to be of a high standard. Only 6 other families said that they had ever considered the possibility of their child living anywhere other than at home in the foreseeable future and none of these had taken any action in the matter.

The long-term future appeared to be the greatest worry for the majority of families. Many parents said that they tried not to think about the future because the thought was too depressing. The majority wanted their handicapped child to stay with them for as long as they could manage to look after them. A few parents said that one or more of their other children had either offered, or agreed, to look after their handicapped sibling and some others hoped that this might happen. Most of them recognised, however, that there could be no certainty about it and that a great deal would depend on the children's own family circumstances and the attitude of their spouses. The majority did not expect their children to take on responsibility for their handicapped sibling because they felt that this would handicap their children's lives in the same way that theirs had been handicapped. There were several

parents who believed that their children could achieve enough independence to manage in sheltered accommodation. One couple were beginning to realise that their son may even be able to cope with marriage in a sheltered situation.

Most of the parents had no clear idea about what they expected to happen. Many regarded the idea of a long-term stay in hospital or 'a home' with horror. One mother said "the thought of him going into a home would finish me", and her husband added, "the day they ever try to come near my door and do that I'm afraid they'll have a shock on their hands". Many parents were afraid that their children would be badly treated in any sort of institution. One mother said that she thought she would give her child an overdose to go with them if she thought she and her husband were about to die.

It was apparent that few of the parents knew much, if anything, about the sort of care that would be available in the long-term though some parents said they had recently received a letter inviting them to visit a new hostel in the county. This was clearly a major area of counselling need.

CONCLUSION

The results of the present study show a continuing high level of problems experienced by the families involved. Five years after the original study the difficulties faced by these families seem to have changed very little. With the advancing age of the children the areas of greatest concern have in some cases altered but overall life in these families continues to be beset with high levels of stress and problems in adjusting family affairs to cope with the effects of the child's handicap.

As the children grow older problems in family management continue to be an area of major concern. Deteriorating health and the problems of involving the child in social and other family activities were reported as particular problems but parents also commented on their own difficulties in enjoying a social life because of the continuing need for "babysitting". At the same time, as the children grew older, many families found it easier to take holidays. Presumably this reflects the changing nature of the problems which the children present. Problems in sleeping, for example, were reported as much less frequent and the majority of the children were seen as having made considerable progress towards independence. These developments clearly make it easier to live in holiday accommodation and to participate in holiday activities. At

the same time, however, some parents reported increased difficulties in lifting and moving their heavier children and many parents commented on a growing number of behaviour and emotional problems which were similarly more difficult to handle as their children approached adulthood and physical maturity.

Housing and the availability of specialist equipment was another area of continuing concern for parents. While some families had moved to more suitable accommodation and others had been able to get appropriate modifications made to their existing houses many families were living in what were increasingly unsuitable conditions. The actual locations of the house (e.g. at the top of a steep hill), stairs within the house and non-adapted bathroom amenities represented serious problems for some families, especially, once again, as their children grow older and heavier and as parents become older themselves and less able to do the lifting and pushing involved. While some parents appeared to have received good support from the Local Authority in these changes others seemed to have experienced a general lack of official interest. Particularly worrying is the extent to which parents had to seek out information about their entitlements and the availability of help from official sources.

Fewer parents reported travelling difficulties on this occasion than had done so in the original study but to some extent this must reflect the fact that more families now had

their own cars. Furthermore, while the use of public transport has apparently become easier with children having become more mobile, parents still report difficulties in access and seating, particularly on local transport. This is an area in which much clearly remains to be done before travel for handicapped people becomes problem free.

For many of the parents the increasing age of their children had resulted in a growing concern for post-school provision. In spite of recent increasing awareness of the need for such provision many problems clearly still remain in obtaining quick and appropriate placements. While 13 of the 15 young people who had left school had been placed in an Adult Training Centre many parents had experienced difficulties and delays in getting these places for their children. Many parents had clearly had to "fight for" what they felt should be a right rather than a privilege. Overall, the parents of the young people who were attending centres were satisfied with what was being provided although some concern was expressed about what was seen as an over-emphasis on "occupational" as compared with "educational" activities.

On the positive side parents appeared to be more satisfied with educational and medical provisions than they had been in the original study. Over half of the children were still at school and the parents of these children were generally positive about what was happening in the schools involved. Parents reported greater contact with schools and a high degree of

appropriateness of the education that was being provided. The lack of speech therapy support in the schools (and in the home) was the only concern that was commonly expressed although some dissatisfaction was voiced about the extent of parental involvement in the assessment process. This latter concern has, however, subsequently been overtaken by the requirements of the 1981 Education Act wherein there is now a statutory obligation for Local Authorities to involve parents in this process. Similarly, many parents reported on the benefits they had derived from the long term relationships they had had with medical specialists, and paediatricians in particular. Some parents reported a lack of sensitivity in hospitals to the problems they experienced in attending out-patient clinics where long waiting periods created severe problems for them. Similarly, seeing different personnel on each visit to a clinic was reported by many parents as being far less satisfactory than the sort of support that they derived from more constant contacts with medical staff.

A continued lack of information about services which are available to the handicapped and their families was reported by the majority of families (only four said that they had had full explanation of relevant forms and procedures). The extent to which parents felt that they needed to "fight for everything all the time", their ignorance of their entitlements and the wide variation in the support which was received, all point to the need for a "named person" to provide this link between families and relevant service agencies.

In the light of this perceived lack of official support the high level of parental involvement in voluntary organisation is not surprising. While some said they did not play a very active role in these bodies they were seen by many families as a major source of emotional support and a vital source of information. These organisations were also seen to provide a major social resource for the handicapped and their families. The informal support of families and friends was also of major importance to many families. The help provided by outsiders was positively commented on by many parents but at the same time the loneliness and isolation which the existence of a handicapped child seems to create had decreased very little as the children had grown older. It is important to note, however, that the publicity which had surrounded the International Year of the Disabled was felt by many parents to have resulted in a greater acceptance of handicap which had, in turn, made their social life easier.

In summary, while in the past five years some improvements have been made in providing more adequate support for families with a handicapped child, life in such families continues to be beset with difficulties. It is clear from this follow-up study that such difficulties do not become any less severe with age - the type of problem presented may change but problems remain. While greater satisfaction was expressed with educational and medical services much clearly remains to be done to make post-school aged provision more easily accessible and to make support in the home more flexible to meet the changing needs of these young people as they grow older.

APPENDIX 1

STRUCTURED INTERVIEW QUESTIONNAIRE

SECTION 1: BACKGROUND INFORMATION

1. Name(s) of parent(s):

2. Address:

3. Name of Child:

4. Sex: Male ☐ Female ☐

5a. Date of Birth: ☐☐☐☐☐☐

b. Age on 1st January 1982 ☐ Years ☐ months

6a. Where does X spend his/her time on weekdays?

Day school	☐
A.T.C.	☐
Home	☐
Weekly Boarding School	☐
Termly Boarding School	☐
in Residential Care	☐
Other	☐

If other, specify

b. Name of school, A.T.C. etc.

7. Are the same people living in your family home as 5 years ago? Yes ☐ No ☐

If No, note changes

8a. Number of adults in household ☐

b. Number of children in household ☐

c. Total ☐

9. Age, Sex and Position of Children in Family (Mark subject of study*):

Position	1	2	3	4	5	6	7
Sex:							
Age:							

10. Status of parents(s):

- Married ☐
- Divorced ☐
- Separated ☐
- Widowed ☐
- Unmarried ☐
- Foster Parent(s) ☐

11a. Age of Father:

b. Age of Mother:

12a. Occupation of Father:

- Working full-time ☐
- Working part-time ☐
- Not working ☐

If not working, note reason:

c. Occupation of Mother:

d.

- Working full-time ☐
- Working part-time ☐
- Not Working ☐

If not working, note reason:

13a. Type of housing:

- house ☐
- bungalow ☐
- flat ☐ Floor No.
- maisonette ☐ Floor Nos.

b. Do you own or rent your home?

- own ☐
- rent ☐
- other ☐

If other, specify:

If rented, note type:

Council	☐
private	☐
H.A.	☐
other	☐

SECTION 2: THE HANDICAP AND ITS SPECIFIC EFFECTS

14. What name is generally given to X's handicap?

15. What specific problems does he/she have?

Checklist:

		Yes	No
a.	Is he/she able to walk without help?	☐	☐
b.	If No: can he/she move about in any other way?	☐	☐
c.	Is he/she able to sit without support?	☐	☐
d.	Is he/she continent (clean and dry)?	☐	☐
e.	If No: Do you receive nappy pads from the Social Services Dept.?	☐	☐
f.	Is he/she able to dress without help?	☐	☐
g.	Is he/she able to feed himself/herself?	☐	☐
h.	Is he/she able to drink from a cup?	☐	☐
i.	Does he/she have any difficulty in chewing and swallowing?	☐	☐
j.	Does he/she have any eyesight problems?	☐	☐
k.	Does he/she have any problems with hearing?	☐	☐
l.	Does he/she have any speech problems?	☐	☐
m.	If Yes: Can he/she make himself/herself understood?	☐	☐

n. Does he/she understand what you say? Yes ☐ No ☐

o. Does he/she ever have fits? ☐ ☐

p. Does he/she have any sleeping problems? ☐ ☐

q. If yes: How does this affect the family? (e.g. who gets up?)

r. Does he/she have any tablets or medicine to help with sleeping? ☐ ☐

16. How would you rate the amount of progress X has made in learning to do things for himself/herself in the last 5 years?

No progress	☐	0
Slight progress	☐	1
Moderate progress	☐	2
Good progress	☐	3

Check: movement
speech
toilet training
dressing
feeding

17a. Has there been any change in his/her general health in the last 5 years? Yes ☐ No ☐

If yes: note details:

b. Has he/she had any spells in hospital in the last 5 years? Yes ☐ No ☐

If yes: note details

How did he/she react?

SECTION 3: PRACTICAL NEEDS AND PROBLEMS: HOUSING, EQUIPMENT ALLOWANCES AND TRANSPORT

18a. Have you moved house during the last 5 years? Yes ☐ No ☐

If yes: note reasons:

b. Has the move made it easier for you to cope with X? Yes ☐ No ☐

If yes: In what ways?

c. Have there been any problems connected with the move?

19a. Have any alterations been made to the house in the last 5 years in order to make it easier to cope with X's disability? Yes ☐ No ☐

If yes:

b. Who carried out the alterations?

c. Who paid for them?

20a. Is there anything about the house which you find inconvenient for X? Yes ☐ No ☐

If yes: note details

b. Have you tried to get anything done about it? Yes ☐ No ☐

If yes: note details

21a. Have you had any new equipment in the last 5 years, either to help you cope with X's disability or to help you to manage the extra work involved? Yes ☐ No ☐

If yes: note nature of equipment

b. Who supplied it?

c. Did you have to pay anything? Yes ☐ No ☐

d. Did you find out about it for yourself or did someone else suggest it might be useful?

e. Did you have any trouble getting it? Yes ☐ No ☐

If yes: note details

22. Is there anything you've asked for but haven't got? Yes ☐ No ☐

If yes: note details

23a. What allowances do you receive?

attendance ☐
mobility ☐
other ☐

(If X is 16 or over)

b. Does X receive the invalidity allowance? Yes ☐ No ☐

c. Do you feel that these are sufficient to cover your extra expenses? Yes ☐ No ☐

24a. Is travelling difficult with X? Yes ☐ No ☐

If yes: In what ways?

b. Have you got your own car? Yes ☐ No ☐

SECTION 4: FAMILY LIFE

25. How does X spend his/her time when at home?

26. Does he/she have any contact with children/ young people his/her own age other than at school/A.T.C.? Yes ☐ No ☐

If yes: note details

27. If X is 13+ (but treat flexibly) Has X had any particular emotional problems associated with growing up? Yes ☐ No ☐

If yes: note type of problem

28a. If X is 15+ (but treat flexibly) What about his/her sexual development and feelings?

How is he/she coping with these?

b. Are you at all anxious about this?

29. What is it about X that you find most difficult to cope with?

30a. If one parent only present
How much of a share do other members of the family have in looking after X?
(Probe: What sort of things does your husband/wife do for him/her? Is there anything he/she doesn't do?)

OR

b. If both parents present
Do you have any way of sharing out the work of caring for X?
(Probe: Do you share it all? Are there some things only one of you does?)

c. If there are sibs.
Do your other children help with X at all? Yes ☐ No ☐

If yes: what sort of things do they do?

31a. Do you ever have an evening out together? Yes ☐ No ☐

OR

b. If single parent:
Do you ever have an evening out? Yes ☐ No ☐

c. If yes: About how often:
Once a week or more ☐
Once a month or more ☐
Twice a year or more ☐
Once a year or less ☐

d. Who looks after X

e. If No: Whould you go if you had a suitable baby-sitter? Yes ☐ No ☐

f. If yes: Who would you consider to be suitable? (e.g. relative, friend, neighbour, parent of handicapped child, someone provided by Social Services Dept.)

32a Have you and/or other members of the family had any holidays during the last 5 years? Yes ☐ No ☐

b. If yes: How many?

c. About how long were you away each time?

d. Which members of the family went?
mother ☐
father ☐
X ☐
other children ☐
other (e.g. grandparent) ☐

If other, specify:

33. If you had an unexpected family problem (e.g. if mother had to go into hospital) who would look after X?

34. Has there been any change in the general health of any members of the family in the last 5 years?

Yes ☐ No ☐

If yes: note details

35. How has X's growing older affected the relationships within the family? (e.g. husband/wife; parents/other children; X/other children)

36. If there are sibs.
Do your other children invite friends to the house?

Yes ☐ No ☐

If No: Why do you think this is?

37. Has X's growing older made any difference to your family's relationships with other people?

Yes ☐ No ☐

If yes: In what ways?:

38a. Have you ever considered the possibility of X living anywhere other than at home? Yes ☐ No ☐

b. If yes: did you do anything about it? Yes ☐ No ☐

If yes: note details:

c. Has anyone else ever suggested this as a possibility? Yes ☐ No ☐

If yes: who was that?

If X already lives away from home:

39. What made you decide to have X placed in residential care/boarding school, etc?

40. If there had been more short-term care available (so that you could have frequent breaks) do you think you would have kept him/her at home? Yes ☐ No ☐

41. How did his/her leaving home affect the rest of the family?

SECTION 5: MEDICAL SERVICES

42a. Does X have to make any regular visits to a hospital or clinic? Yes ☐ No ☐

If yes:

b. Who usually takes him/her?

c. How often do you go?

d. How do you get there?

Probe: Does the journey present any problems?

43. Who do you see?
(e.g. paediatrician, speech therapist, etc.)

a. (1st person seen)

(1) How long do you usually have to wait?

Probe: How does this affect you and X?

(2) Do you see the same person each time? Yes ☐ No ☐

(3) How long do you spend with him/her

(4) Does he/she explain things to you as much as you would like? Yes ☐ No ☐

(5) Do you feel that he/she takes notice of what you have to say? Yes ☐ No ☐

b. (2nd person seen)

(1) How long do you usually have to wait?

Probe: How does this affect you and X?

(2) Do you see the same person each time? Yes ☐ No ☐

(3) How long do you spend with him/her?

(4) Does he/she explain things to you as much as you would like? Yes ☐ No ☐

(5) Do you feel that he/she takes notice of what you have to say? Yes ☐ No ☐

c. (3rd person seen)

(1) How long do you usually have to wait?

Probe: How does this affect you and X?

(2) Do you see the same person each time Yes ☐ No ☐

(3) How long do you spend with him/her?

(4) Does he/she explain things to you as much as you would like? Yes ☐ No ☐

(5) Do you feel that he/she takes notice of what you have to say? Yes ☐ No ☐

44a. From your point of view, how useful are these visits?

Probe: Do you get any helpful advice?

b. Can you think of anything that would improve these visits?

c. Has the situation changed at all during the last 5 years? Yes ☐ No ☐

If yes: In what ways?

45a. Do you make any other visits in connection with X's disability? Yes ☐ No ☐

If yes: note details

b. How convenient are these visits? (e.g. travel, length of wait)

c. How useful do you find these visits? (e.g. Do they explain, listen, give helpful advice?)

d. Can you think of anything that would improve these visits?

e. Has the situation changed at all during the last 5 years? Yes ☐ No ☐

If yes: In what ways?

46a. How often does X see your G.P.?

b. Does he/she give you any helpful advice? Yes ☐ No ☐

c. Does he/she take an interest in the whole family's needs and problems? Yes ☐ No ☐

d. Are there any problems when you visit the surgery with X? Yes ☐ No ☐

e. Is the doctor happy to visit X at home? Yes ☐ No ☐

f. Has the situation changed at all during the last 5 years? Yes ☐ No ☐

If yes: In what ways?

47a. Do you have any visits to your home in connection with X's disability? Yes ☐ No ☐

If yes: note details

b. How useful do you find these visits?

48. Is there anyone else from whom you would welcome visits at home?

49a. Is there anyone involved in X's care who visits him/her at school? Yes ☐ No ☐ Don't know ☐

If yes: note details:

b. Are you invited to be present? Yes ☐ No ☐

c. Do you usually go? Yes ☐ No ☐

d. How useful do you find these visits?

50. Have you ever tried to get specialist advice or help for X other than that available from the National Health Service? Yes ☐ No ☐

If yes: note details and outcome:

SECTION 6: EDUCATION

If X is still at school

51a. Has X changed schools during the last 5 years? Yes ☐ No ☐

If yes: note reasons

b. If YES
Did you share in the decision? Yes ☐ No ☐

52a. What sort of contact is there between you and the school?
(e.g. home visits, home/school book, etc.)

b. Would you like to have more contact than this? Yes ☐ No ☐

53. When you see the teachers, do you feel they take notice of what you have to say about X? Yes ☐ No ☐

54a. Have you been given any guidance during the last 5 years about how you can help at home with X's learning? Yes ☐ No ☐

b. If yes: By whom?

c. If No: Would you have welcomed this sort of help? Yes ☐ No ☐

55a. Does the school have a P.T.A.? Yes ☐ No ☐

b. If yes: Do you go to the meetings? Yes ☐ No ☐

c. Have you found them helpful? Yes ☐ No ☐

If yes: In what ways?

56a. Are you satisfied with the present arrangements for X's education? Yes ☐ No ☐

b. If yes: Are there any changes you would like to see?

OR c. If No: What sort of changes would you like to see?

d. What do you feel X has gained most from his/her time at school?

57a. Have you ever asked for or been offered a home teacher for X? Yes ☐ No ☐
If yes: note details and outcome

b. If No: Do you think this would be/have been helpful for X? Yes ☐ No ☐

c. Have you ever paid for private teaching for X? Yes ☐ No ☐

If yes: note details and outcome

58a. If X is 15+
At what age do you expect X to leave school?

b. Have you been invited to join in any discussions about what he/she will do then? Yes ☐ No ☐

c. Has anyone talked to you about it at all? Yes ☐ No ☐

59. Do the school holidays present any problems? Yes ☐ No ☐

If yes: What sort of help could you do with then?

(If X has left school)

60a. At what age did X leave school?

b. Did you feel that he/she was ready to leave? Yes ☐ No ☐

61a. Who decided where X should go after leaving school?

(If parents not mentioned)

b. Did you share in the decision? Yes ☐ No ☐

c. If No: Did anyone discuss it with you beforehand? Yes ☐ No ☐

d. Did anyone talk to X about it? Yes ☐

No ☐

He/she wouldn't have understood ☐

e. How long before he/she left school did you know where he/she was going?

62. Did X have any difficulty in adjusting to no longer being at school? Yes ☐ No ☐

If yes: In what ways?

63. How did his/her leaving school affect you and the rest of the family?

64. Are you satisfied with the present provision for him/her? Yes ☐ No ☐

If No: What sort of provision would you like to see?

SECTION 7: SUPPORT

65a. Do you have any help from the Social Services? Yes ☐ No ☐

b. If No: Have you asked for any? Yes ☐ No ☐

c. If yes: What sort of help do they give you?

66. Have there been any new forms of help offered to you in the last 5 years? Yes ☐ No ☐

If yes: note details:

67. Has anyone ever explained to you all the forms of help that are available or have you ever received a booklet which explains them? Yes ☐ No ☐

68. Do you think that the services work together any more than they did 5 years ago? Yes ☐ No ☐

If yes: In what ways?

69. Have you ever been invited to attend a discussion group with other parents of handicapped children? Yes ☐ No ☐

If yes: note details and reactions:

70a. Do you belong to any voluntary organisations for parents of children with handicaps? Yes ☐ No ☐

b. If yes: Has the organisation helped you in any specific way?

c. Have you found it helpful to meet with other parents with similar problems? Yes ☐ No ☐

If yes: In what ways?

d. If not members: Have you ever been contacted by any such organisation? Yes ☐ No ☐

e. If yes: Why did you decide not to join?

f. If No: Would you have welcomed such contact? Yes ☐ No ☐

71a. Do you have any relatives living near you? Yes ☐ No ☐

b. If yes: Do you have any help from them? Yes ☐ No ☐

c. If yes: What sort of help do they give you?

72a. Do you have any help from neighbours? Yes ☐ No ☐

b. If yes: What sort of help do they give you?

73a. Do you have any help from friends? Yes ☐ No ☐

b. If yes: What sort of help?

74a. Do you have help from anyone else? (e.g. a local society, Church, youth club, etc.) Yes ☐ No ☐

b. If yes: What sort of help?

75. Can you think of any kind of help you would like but are not getting?

76a. Do you ever feel particularly lonely or isolated? Yes ☐ No ☐

b. If yes: Would you say it was often/ sometimes/occasionally?

77. If you wanted general help or advice who do you think you would turn to?

78. Have your feelings about the prospects for X's future changed much as he/she has grown older? Yes ☐ No ☐

If yes: In what ways?

79. Do you think that the International Year of Disabled People has made any difference to people's attitude or made them more willing to help? Yes ☐ No ☐

If yes: In what ways?